

Telling the Truth – All of It

by Brenda Denzler

When you get a cancer diagnosis, the first few weeks are a whirlwind. There are tests to be done, doctors to be seen, information to be conveyed and plans to be made. As a patient, you are in shock and trying hard to focus your mind on what the doctors are saying. You don't focus a lot on any other issues—like what your life will be like once your treatments are finished. All you care about—all you can think about—is “Get that cancer out!”

It's not hard to ignore the question of what happens after that, because among all the things doctors discuss with you at such times, the long-term effects of the treatments they propose are almost never discussed—and if they are, it's very seldom in depth. At one point or another, the patient hears or reads the happy catch-phrase “your new normal.” By referencing what life was like before cancer (“normal”), the phrase conjures up images of a return to that condition. Maybe minus a prostate or a section of colon or a breast.... Maybe with a risk for lymphedema. Hence the “new.” But otherwise, a return to your old self, your old life.

However, the “new” in “new normal” includes a lot of other changes that many cancer survivors experience but are not warned about—changes that may preclude a return to your old life. Prominent among them is fatigue. Not “tiredness” like you get when you've worked hard doing yardwork all day, but “fatigue”—a condition of diminished ability to function at your customary level and duration due to physical weakness and exhaustion that is unrelieved by rest.

The medical lit says about 1/3 of survivors complain of this. Most doctors implicitly or explicitly say it's the patient's fault for not being active enough and that the best remedy is for them to get up off their duffs and exercise. If the

patients are female, there is a disproportionate chance that the diagnosis will be not just sloth, but also some psychological issue like depression or anxiety.

Under no circumstances will the oncologist look you straight in the eye and say, “Yes, our treatments caused this. It’s a long-term side effect that some people have. We don’t know much about it, yet, but it appears to be permanent. I’m really sorry, but it’s the price of your being alive at all right now. You’re going to have to figure out how to move forward with this situation. If I can help you with that, please let me know.”

While most of the oncology community goes about its business with its head in the sand, pleased as punch (rightfully so) when they’ve managed to put the cancer into remission and more or less oblivious (sadly) to what else happens in the long run because of that, some medical researchers have begun paying attention.

- A 2007 article in *The Oncologist* reviewed the possible biological mechanisms of long-term cancer fatigue.
- By 2012, studies reported in the *Journal of Pain and Symptom Management* said that cancer-related fatigue was probably caused by a failure of the central nervous system to properly manage the functioning of the muscles.
- The year 2013 was a banner year. There were not just one but **two** reports in the medical literature (*Biological Journal for Nursing* and the *Journal of Clinical Oncology*) discussing long-term changes in the patient’s genetic structure or the genes’ surrounding cellular environment as causes of post-treatment fatigue, noting that increased levels of inflammatory substances could be the culprit.
- The next year, no less a publication than the *Journal of the National Cancer Institute* reported that in women who had received certain types of

chemotherapy for breast cancer, cellular-level markers of aging were the same as for women who were almost 15 years older! The study authors suggested that chemo had caused damage to the stem cells, which then passed the damage down to future generations of cells.

- Keeping up the momentum, in 2017 Ned Sharpless, formerly the director of the Lineberger Cancer Center and now the head of the National Cancer Institute, gave Grand Rounds at UNC Hospitals on the topic of premature cellular aging in cancer survivors.

And the beat goes on.....

Last summer, I read an article talking about extraordinary fatigue and muscular weakness in astronauts who spend a long time on the space station. Despite their in-space exercise routine, they gradually develop the same kinds of fatigue and weakness symptoms that (I realized) cancer survivors report. I wrote to the study's lead investigator to ask if he'd thought of testing such long-term survivors—and he already had! In fact, he and his team published these results in 2016 (*PLoS ONE*) and in 2017 (*Journal of the American Heart Association*).

The symptoms reported by astronauts and some long-term cancer survivors, he said, are pretty much the same. They seem to be caused by changes in the microvasculature. The only difference, he said, is that it's reversible for the astronauts, who can return to gravity, whereas it appears not to be for cancer survivors, who cannot un-take their cancer treatments.

This growing body of evidence about the biological basis of serious, long-term, post-treatment fatigue has yet to make its way into the consciousness of most oncologists, it would appear, much less into the counseling given to new patients about what to expect from treatment.

How could it? For every article that's been published in medical journals about the deleterious long-term effects of cancer treatment, there are a dozen articles published in those same journals about how exercise improves everything.

For every time-consuming, painstaking, laborious and expensive bit of laboratory science focused on indisputable biological factors in post-treatment fatigue and weakness, there are a dozen quicker-and-easier studies usually focused on small groups of recent (few or no truly long-term) survivors who self-report their symptoms before and after exercise regimens of limited duration.

Cancer treatment can be life-saving. It can also be life-changing—and not in that wonderful, fluffy, “positive thinking” way that extols the virtues of enduring hardship. Newly diagnosed patients need to be given the facts, fairly presented, so that they are not blindsided if, instead of getting better and better after their treatments, they slowly get worse and worse. This can be considered a fair trade-off for the chance to live longer...but, like the chance of getting lymphedema or a secondary cancer, it needs to be a risk you take with your eyes wide open.

Patients need the truth, the whole truth. All at once. Up front. Not piecemeal, with some of the cold, hard truths about treatment risks becoming painfully obvious only after the fact. And for those of us who struggle daily with the price we have paid to be alive there needs to be unquestioned support from the oncologists who helped to do this—not a blind eye turned and parting suggestions as they leave the exam room that we get some exercise and take a Prozac.

Brenda Denzler was diagnosed with inflammatory breast cancer in 2009. She became a cancer survivor on the very day she was diagnosed.

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