

An evening with Ben Goldacre

Last night was a real treat. Along with my eldest son and his wife I attended the Auckland evening with Ben Goldacre, author of “Bad Science” and “Bad Pharma.” There’s also another book on the way – on statins.

I doubt that I have ever met anybody who can talk as fast as that man. And he sure managed to cover an awful lot of scientific and medical information in the couple of hours we had of listening to him talk, then be interviewed, and finally answer questions.

The Mercury Theatre was packed. And he gave us all a highly entertaining, evidence-based tiki tour of exactly how science and the pharmaceutical industry have let us down, and what we can do about it. Join the AllTrials campaign for a start! It’s one of Ben Goldacre’s international initiatives –

<http://www.alltrials.net/>

I have been a big fan of Ben Goldacre since I read his first book, “Bad Science,” five or six years ago. And I was one of hundreds who registered to attend his lecture at the Auckland Writers and Readers Festival a couple of years ago, and was so disappointed when he didn’t make it. His wife was having an extremely hard time with morning sickness so he elected to stay in the UK and look after her. So of course I forgave him and thought how wonderful he was to do that, given the pressure he must have been under to show up on the other side of the world despite his wife being pregnant and very sick.

The cherry on the rich cake that was last night was having my photo taken with him!





Living with uncertainty

The most difficult bit about what's happening now is that there isn't much happening.

I'm in the in-between phase that lots of cancer patients experience once their treatment ends. For those of us with a diagnosis of terminal cancer who have had some form of palliative treatment, once this has ended there is this unknown length of time ahead during which we try to carry on with our lives outside of the health system, but at the same time are keenly aware of any new symptoms or the return of familiar ones. What is going on inside my diseased body, I wonder? Is the discomfort getting worse because the cancer is spreading or am I just imagining things. The uncertainty is

hard to live with.

For those cancer patients whose surgery, chemotherapy, and/or radiotherapy were attempts to cure their cancer, there is the hope that they have been cured, and they have years of life ahead of them. Yet, there is no guarantee that the cancer won't return, and they, too, must learn to live with some degree of uncertainty.

Everyone tells me how well I look. My hair is growing back, and ten days ago I gave up wearing my wig, and now wear hats when I go out. I am working towards not feeling the need to wear a hat, and I am now able to look at myself in the mirror without wearing my wig or a hat. These things are major achievements for me.

I am due to have another CT scan in a month or so. I have mixed feelings about this. While I find it difficult to live with this uncertainty, and keep wondering how long I have got left, dealing with the CT scan result may be even more challenging. As with the previous CT scans I will not allow myself the luxury of hope. The only way I have of coping with my situation is to stay off the roller coaster. I can handle good news, but not disappointment.

In the meantime I am now down to twice weekly dressing changes for the wound on my neck.

Another “fighter” who is “battling cancer”

A recent media commentary on *Radio NZ* suggested that it was time to declare war on cancerous clichés, saying that the

medical profession had begun to question whether the use of military-style metaphors such as “battling cancer” are bad for a patient’s health. Doctors think that “viewing disease as an enemy or something that has to be fought against is not helping patients cope with their illness.” Health professionals are not the only ones protesting such expectations being laid on patients. Some of us cancer patients are also sick of being told we are engaged in a war on cancer.

The latest victim of such media clichés is National Party MP Nikki Kaye. Not only is she having to put up with the Prime Minister telling the world that “she is young, she is very fit, she’s extremely determined and she’s a fighter,” the *NZ Herald*’s political editor also saw fit to claim that “Nikki Kaye is battling breast cancer” and that “she won’t be just fighting cancer. She will be declaring war on it with every fibre of her being.” How dare these people think they have the right to publicly air their opinions about how anyone will deal with their cancer diagnosis!

As *Mediawatch* pointed out “when it comes to cancer there is one metaphor that’s long since become a cliché that just refuses to die.”

Apparently stuff.co.nz and the *NZ Herald* website has used the phrase cancer battle more than 50 times so far this year. “And one of those stories highlighted the fact that the person who had died refused to use the word battle to describe her experience of living with cancer.”

Well, if the story on the *Herald* website was the one about me that also featured a short interview in which I said very firmly that I was definitely not battling the terminal cancer I had been diagnosed with, then I feel the need to protest that the news of my death has been greatly exaggerated.

“It is time that the media declared war on cancer clichés and

stopped framing stories about life and death in terms of winners and losers." I'll drink to that!

<http://www.radionz.co.nz/national/programmes/mediawatch/audio/201811941/declaring-war-on-cancerous-cliches>

More books

While holidaying at Pukehina beach, I finished reading "Malignant" a book lent to me by a friend, that tells the stories of seven people, all experts in the field of medical ethics, whose personal experiences with cancer showed them how little they understood about what happens when they or their spouse were diagnosed with cancer. Despite years of teaching and writing about treatment decision-making and patient autonomy, these professionals were unprepared for many of the problems they faced and were often shocked by their experiences. Knowing more about the medical system than most patients did not help them when faced with the life-changing words "You have cancer."

I found much that I related to in the chapters on diagnostic quests and accidents, hearing the bad news, coping with uncertainty, patient autonomy, volunteering for research, resilience and the art of living in remission, the allure of questionable-benefit treatment, cancer stereotypes, cancer and mortality, and survivorship. There were also experiences I did not relate to, but many were nonetheless helpful to me as I navigate my own way through living with terminal cancer.

I then began reading Susan Gubar's "Memoir of a Debulked Woman" which is an incredibly confronting account of her diagnosis in 2008 of ovarian cancer and the various treatments she underwent. This book is definitely not for the faint-

hearted as she chronicles in harrowing detail the elective hell of her invasive cancer treatment. Her “suboptimal” surgery resulted in unexpected and ghastly outcomes, ongoing infections, and months of coping with extreme pain. Her story not only put my moaning about how long it is taking for the wound on the back of my neck to heal in perspective, it also made me feel extremely grateful that I had not been a candidate for Whipple’s surgery, another debulking operation that some pancreatic cancer patients are offered.

Having googled Jenny Diski, author of “In Gratitude,” and discovered that she died in April 2016 soon after her book was published, and then Cory Taylor, author of “Dying: a memoir,” and found that she died in July 2016 soon after her book was published, I was somewhat reluctant to investigate whether Susan Gubar was still alive. Given that most ovarian cancer patients, like pancreatic cancer patients, also do not survive for very long, and it had been four years since her book was published I expected the worst.

However a recent sleepless night found me at my computer undertaking more googling, resulting in the news that not only is Susan Gubar still alive she is blogging for the *New York Times* with her recent blog dated 26 August 2016:

http://well.blogs.nytimes.com/author/susan-gubar/?_r=0

I then went looking to see if anyone had written a book about their experience of pancreatic cancer, and found Bob Brown’s “The Ride of My Life: A fight to survive pancreatic cancer.” Despite my objections to all the unremitting and unhelpful battle terminology that surrounds cancer patients, I have ordered the book – because Bob Brown died in 2013.