

Diagnosis + 6 Days

Kcuf Recnac

by Steven Saltman

Acknowledgements

I would like to thank the MBTA subway and bus system, without which I could never have made it on time to chemotherapy and radiation. Maybe wife could have driven me, but then again, she probably had better things to do, and if I knew what those things were we might not have gotten divorced.

I would also like to apologize to my parents for getting cancer. If my kid gets cancer I will certainly act a lot less sane than my parents did. Shit, they still think the world is a good place. Now that's faith.

I would like to acknowledge the power and wonder of narcotic drugs. Unless you've been through serious pain, you don't know how awesome narcotics are. Well, maybe that's not true. Maybe you do know how awesome narcotics are and you've never been through serious pain and if so then you probably have a drug problem. You would still agree with me that narcotics are pretty awesome, but you are not so awesome and you should get help by going to a posh rehab clinic where you can hit on hot celebrities while you are treated for 'exhaustion'.

So I have to acknowledge Leo Henryk Sternbach, inventor/discoverer of benzodiazepines. You can read about him for free in Google books, a place where copyrights are a thing of the imagination. I'm sure my book will be there eventually, tossed into the heap of public domain content like a dog turd in a public park.

And if you think it's weird to thank a drug, imagine how crazy it is thank a drug-maker. I once had the privilege of having dinner in Brazil with the heir to the Sandoz Pharmaceutical fortune. I mentioned my cancer to him and told him "thank you" for developing all the horrible, mutagenic, nausea-inducing, corrosive drugs that went into my chemotherapy cocktail and cured my illness. He looked at me with true surprise and said he had never been thanked for making drugs. But I suppose I shouldn't thank him, I should acknowledge all the dead cancer patients who went before me; those who died horribly and slowly taking the precursors to the drugs I took, drugs that made you ill to the point of death and may very well have simply made your last days shorter and eviler than no drugs at all.

When I was first diagnosed, one of my doctors, who had been treating patients since the 1950's told me, "We'll cure you even if you are stage IV. When I first started working in oncology all my patients died, now most of them live." Now that's the true wonder of modern medicine.

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TGWGMC

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Preface

I started writing this book in 1996, when I was diagnosed and started going through treatment for Hodgkin's lymphoma a.k.a. cancer. I participated actively in the Hodgkin's List Server by e-mail, which is still online at www.deltronix.com/public/li/listserver.html.

The Internet barely existed back then. Folks were on America Online and participated in list servers to communicate with groups. List servers are basically e-mail engines or remailers. You subscribe and send an e-mail and the e-mail goes out to all the subscribers. If you use Yahoo Groups, you know what this is like. The Hodgkin's List Server was very important to me and provided a means of communication in an age when meeting other cancer patients was difficult. I say without a doubt that it may very well have saved my life, because it certainly saved my sanity.

The Hodgkin's List Server deserves its own book, and I'm not the one to write it. In the few years it was active, friendships were formed, people died, people met and married, lives were changed. It was a magical and awful place, comprising a varied group of individuals brought together in a new electronic medium while fighting for their very lives.

I had a home page on AOL that I called "Kcuf Recnac" and I sold "Kcuf Recnac" and eventually "Fuck Cancer" mugs from my home while I went through treatment. I got the idea for Kcuf Recnac from an article I read in the *New Yorker* magazine about a woman who had been bankrupted by investing in Lloyds of London and who put a bronze plaque on her house that read "SDYOLL KCUF." I sold my first Fuck Cancer mug in 1996. I eventually moved that operation to CafePress (www.cafepress.com/humorosis) and added a bunch of other diseases. For a long time I donated most of the profit from those sales to Planet Cancer (now part of the Lance Armstrong Foundation), run by my old friend Heidi Adams, another survivor and all-around fantastic human.

Much of this book was written as mass e-mails to my patient and open-minded friends and the Hodgkin's List Server. I quote liberally from messages I received, and my quotes may or may not be accurate, though with cut and paste, one would think errors are unlikely. The names of list server members have been changed to protect their privacy.

Any mistakes, errors, omissions, and annoyances are my own and are purely the result of my own stupidity, callousness, unfeeling selfishness, narcissism, omphalocentrism, and ignorance.

This book contains foul language, bad grammar, misplaced modifiers, dangling participles, references to bodily fluids and sex, disparaging remarks about the traditional medical establishment, disrespect for alternative medicine, and references to my ex-wife.

Read at your own risk. Do not prepare food on this book.

Introduction

I survived cancer. Actually, that's a lie. You don't survive cancer; you merely live with the fact that you're not undergoing treatment for it. It can return anytime, like a *Mafia* hit man. Cancer survivors are really just in a Medical Witness Protection Program ("MWPP"), keeping their fingers crossed that TGWGUC ("The Guy Who Gave Us Cancer") won't strike again.

I use a lot of acronyms when discussing cancer. I talk about TGWGUC and I also talk about TGWGMC ("The Guy Who Gave **Me** Cancer"). I'm not sure if this is the same guy, but it could be, and if you know him, you'd better tell him to have a taster check his rigatoni 'cause one day it's gonna be full of the extra *Adriamycin* I kept from treatment and he's gonna be real sorry. I also use acronyms because I've had a lot of chemotherapy and chemotherapy is known to alter your ability to think straight. For example, two people are walking down the street. They both trip and fall simultaneously. The first one gets up, looks embarrassed, and HAS NO EXCUSE. The second one gets up, brushes himself off, and says apologetically, "Sorry, I'm going through cancer treatment," at which point hundreds, nay thousands, of people come rushing to give the guy a hand and fistfuls of cash out of sympathy, pity, what-have-you. Thus, I use acronyms.

An important acronym to remember when reading this book is TGWGTGWMCC. This is a long acronym and difficult to pronounce. When pronounced properly it sounds a lot like blowing your nose. However, it's really not meant to be pronounced at all. It's more of a *Zen* acronym. You are supposed to read it silently and contemplate the full meaning of it. Because this is the acronym that I am seeking to become. This acronym is one of the many paths of life that I wish to tread upon. It stands for "The Guy Who Gave the Guy Who Gave Me Cancer Cancer." Yes, this is what I want to become.

Ok, it's not really a lofty or noble goal. Nor is it really something that I tell to people I meet in the supermarket or in job interviews, but it's something. I'm not sure how to become TGWGTGWMCC, because I'm not sure who TGWGMC is. In fact, I'm not even sure that I can find out. So even the goal itself is more of a contemplative thing. Just thinking about it is part of the process.

OK, enough about me. Obviously somebody you know well has cancer. Or perhaps you have cancer. Or perhaps you bought this book because you think you might have cancer. Even if you don't have cancer, you may very well get cancer someday. Hey, you say, that's really morbid. Well, I say, that's life. We are all morbid. Of course, you may get hit by a bus on the way out of the bookstore or your house or you might drink too much and drown in your own vomit, but let's not dwell on the possibilities.

Cancer. Cancer. Cancer. Cancer.

Can we say it again, louder this time? Just a few decades ago it was considered very uncouth to say "cancer" out loud. It brought up too many bad feelings. Getting cancer was a death sentence. Nowadays, however, with modern medicine far advanced, cancer is less of a death sentence than

a conviction with a sentencing hearing to be held at a later date. Many people live through cancer treatment and go on and have healthy, useful, productive lives. Unfortunately, some of those people go into politics, but what can you do?

When I was 30 years old I was diagnosed with Hodgkin's lymphoma aka Hodgkin's disease aka malignant lymphoma aka nodular sclerosing lymphatic cancer. This was not really good news, since I had gotten married just a few months before and I expected to have a long, productive, useful life. Dying of cancer in my early thirties wasn't in my plans. But it happened (the cancer, not the dying). So there you have it.

I'm 30 years old and I have cancer. What a great moment.

Ahh, diagnosis day. D-Day. That was a great day. Great in the important sense not in the "really good day" sense. It's like the day that you find out...find out...find out you have cancer. Actually, there's really nothing like it all. Will you have treatment? Will you have children? Will you have your own birthday cake ever again? Many questions and no answers. Kind of like walking into the SATs, only you're in France and it's the dreaded TASs and you don't speak any French.

What to do if you are diagnosed with cancer:

1. Punch the doctor who gave you the bad news. This is called "blaming the messenger" and makes you feel much better.
2. Panic.
3. Don't go to Cleveland. If you live in Cleveland, stay indoors.

OK, just kidding. I didn't punch the doctor and if you live in Cleveland and the weather is nice, feel free to go outside. I'm not sure what I did. Those first few days are a haze of numbness and despair. I know for a fact that I decided not to drop my heroin habit. I mean, why stop now? I also stopped worrying about my cholesterol count and my fat intake.

What to do if you are diagnosed with cancer – actually helpful tips:

1. Get a second opinion on your diagnosis.
2. Get a third opinion on your diagnosis.
3. There are no other useful suggestions.

There are several good reasons you want a second opinion, not the least of which is that you might not have cancer. Another reason is that you get a chance to punch another doctor. (Note: if you punch every doctor who diagnoses you with cancer, eventually the word will get out and you will get a clean bill of health or you'll be arrested.)

It is important to get a second opinion because diagnoses of disease have been known to be wrong, like car repair estimates. When an automobile mechanic is estimating repairs on your car, he performs the following scientific calculations. First, he looks at you and determines whether you have “sucker” written on your forehead. Then he checks your shoes to see how much money you blow on fashion. Then he comes up with a number that represents his monthly boat payments adjusted for how unhappy he is.

Diagnosis of cancer is done much the same way:

One or more of the following is removed from your body: blood, stool, urine, lymph, tissue, brain, tumor, muscle, spit, eye goo, money. This substance is sent to a laboratory somewhere in the Midwest. A group of overworked technicians who are on leave from beauty school and have prescription drug habits place the substance in a large machine. The machine prints out a random report. The beauty school dropouts send this report to a processing center, which bills your insurance company as much money as possible. The billing code for this is AMMAP, a common medical billing code. Your unsuspecting doctor, who is very concerned about his boat payments and how to keep his children from becoming interested in a career in medicine, gets the report, which says that you probably have cancer. He tells you that you have cancer. You punch him.

He could be wrong. In fact, it is very possible that he is wrong. My doctor wasn't wrong, but I was lucky (hard to figure that one out). Your doctor could be wrong about many things. He could be wrong about the disease. You might not have cancer; you might have hemorrhagic fever or you could have Parkinson's disease or you could have a zillion other illnesses that look like cancer but aren't. You could have a disease so horrible that you'll wish you had cancer. I won't mention them, since if I do I'll get letters from people with those horrible diseases saying that their horrible disease isn't REALLY SO BAD and I should shut my stupid, cancerous trap. Well, those people, who are mostly lying in hospital beds watching their own limbs deteriorate into soup and fall off, can bite me.

Anyway, your doctor could be right about cancer but could be wrong about the type. This is common with lymphoma. I had Hodgkin's lymphoma. But there is also non-Hodgkin's lymphoma. That's right. You heard it correctly. Aren't doctors clever? And get this: non-Hodgkin's lymphoma is still cancer. So you could have non-Hodgkin's but still have cancer. Whoever came up with that should be forced to handwrite a dictionary.