

The Guardian



Smile! You've got cancer

Cancer is not a problem or an illness – it's a gift. Or so Barbara Ehrenreich was told repeatedly after her diagnosis. But the positive thinkers are wrong, she says: sugar-coating illnesses can exact a dreadful cost

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If you had asked me, just before the diagnosis of cancer, whether I was an optimist or a pessimist, I would have been hard-pressed to answer. But on health-related matters, as it turned out, I was optimistic to the point of delusion. Nothing had so far come along that could not be controlled by diet, stretching, painkillers or, at worst, a prescription. So I was not at all alarmed when a routine mammogram aroused some "concern" on the part of my gynaecologist.

How could I have breast cancer? I had no known risk factors, there was no breast cancer in the family, I'd had my babies relatively young and nursed them both. I ate right, drank sparingly and worked out. When the gynaecologist suggested a follow-up mammogram four months later, I agreed only to placate her.

The result of the mammogram, conveyed to me by phone a day later, was that I would need a biopsy, and, for some reason, a messy, surgical one with total anaesthesia. Still, I was not overly perturbed and faced the biopsy like a falsely accused witch confronting a trial by dunking: at least I would clear my name. I called my children to inform them of the upcoming surgery and assured them that the great majority of lumps detected by mammogram - 80%, the radiology technician had told me - are benign.

My official induction into breast cancer came 10 days later with the biopsy, from which I awoke to find the surgeon standing perpendicular to me, at the far end of the bed, down near my feet, stating gravely, "Unfortunately, there is a cancer." It took me the rest of that drug-addled day to decide that the most heinous thing about that sentence was not the presence of cancer but the absence of me - for I, Barbara, did not enter into it even as a cation, a geographical reference point. *I* had been replaced by *it*, was the surgeon's implication.

I know women who followed up their diagnoses with weeks or months of self-study, mastering their options, interviewing doctor after doctor, assessing the damage to be expected from the available treatments. But I could tell from a few hours of investigation that the career of a breast cancer patient had been pretty well mapped out in advance: you may get to negotiate the choice between lumpectomy and mastectomy, but lumpectomy is commonly followed by weeks of radiation, and in either case if the lymph nodes turn out, upon dissection, to be invaded - or "involved," as it's less threateningly put - you're doomed to months of chemotherapy, an intervention that is on a par with using a sledge hammer to swat mosquitoes.

The pressure was on, from doctors and loved ones, to do something right away - kill it, get it out now. The endless exams, the bone scan to check for metastases, the hi-tech heart test to see if I was strong enough to withstand chemotherapy - all these blurred the line between selfhood and thing-hood anyway, organic and inorganic, me and it. As my cancer career unfolded, I would, the helpful pamphlets explained, become a composite of the living and the dead - an implant to replace the breast, a wig to replace the hair. And then what will I mean when I use the word "I"? I fell into a state of unreasoning passive aggressivity: they found it, let them fix it.

Fortunately, no one has to go through this alone. Forty years ago, before Betty Ford, Rose Kushner, Betty Rollin and other pioneer patients spoke out, breast cancer was a dread secret, endured in silence and euphemised in obituaries as a "long illness". Today, however, it's the biggest disease on the cultural map, bigger than Aids, cystic fibrosis or spinal injury, bigger even than those more prolific killers of women - heart disease, lung cancer, and stroke. There are hundreds of websites devoted to it, not to mention newsletters, support groups and a whole genre of first-person breast cancer books.

The first thing I discovered as I waded out into the relevant sites is that not everyone views the disease with horror and dread. Instead, the appropriate attitude is upbeat and even eagerly acquisitive. There is, I found, a significant market for all things breast cancer-related. You can dress in pink-beribboned sweatshirts, denim shirts, pyjamas, lingerie, aprons, shoelaces and socks; accessorise with pink rhinestone brooches, scarves, caps, earrings and bracelets; and brighten up your home with breast cancer candles, coffee mugs, wind chimes and night-lights. "Awareness" beats secrecy and stigma, of course, but I couldn't help noticing that the existential space in which a friend had earnestly advised me to "confront [my] mortality" bore a striking resemblance to a shopping centre.

This is not entirely a case of cynical merchants exploiting the sick. Some of the breast cancer accessories are made by breast cancer survivors themselves, and in most cases a portion of the sales goes to breast cancer research. It is also clear that the ultrafeminine theme of the breast cancer marketplace - the prominence, for example, of cosmetics and jewellery - could be understood as a response to the treatments' disastrous effects on one's looks. There is no doubt, though, that all the prettiness and pinkness is meant to inspire a positive outlook.

I needed whatever help I could get, and found myself searching obsessively for practical tips on hair loss, how to select a chemotherapy regimen, what to wear after surgery and eat when the scent of food sucks. There was, I soon discovered, far more than I could usefully absorb, for thousands of the afflicted have posted their stories, beginning with the lump or bad mammogram, proceeding through the agony of the treatments, pausing to mention the sustaining forces of family, humour and religion, and ending, in almost all cases, with an upbeat message for the terrified neophyte.

I couldn't seem to get enough of these tales, reading on with panicky fascination about everything that can go wrong - septicemia, ruptured implants, startling recurrences a few years after the completion of treatments, "mets" (metastases) to vital organs, and - what scared me most in the short term - "chemobrain" or the cognitive deterioration that sometimes accompanies chemotherapy. I compared myself with everyone, selfishly impatient with those whose conditions were less menacing, shivering over those who had reached Stage IV (there is no Stage V), constantly assessing my chances.

But, despite all the helpful information, the more fellow victims I discovered and read, the greater my sense of isolation grew. No one among the bloggers and book writers seemed to share my sense of outrage over the disease and the available treatments. What causes it and why is it so common, especially in industrialised societies? Why don't we have treatments that distinguish between different forms of breast cancer or between cancer cells and normal dividing cells? In the mainstream of breast cancer culture, there is very little anger, no mention of possible environmental causes, and few comments about the fact that, in all but the more advanced, metastasised cases, it is the "treatments", not the disease, that cause the immediate illness and pain. In fact, the overall tone is almost universally upbeat. The Breast Friends website, for example, features a series of inspirational quotes: "Don't cry over anything that can't cry over you"; "When life hands out lemons, squeeze out a smile"; "Don't wait for your ship to come in... swim out to meet it," and much more of that ilk.

As in the Aids movement, upon which breast cancer activism is partly modelled, the words "patient" and "victim," with their aura of self-pity and passivity, have been ruled un-PC. Instead, we get verbs: those who are in the midst of their treatments are described as "battling" or "fighting", sometimes intensified with "bravely" or "fiercely" - language suggestive of Katharine Hepburn with her face to the wind. Once the treatments are over, one achieves the status of "survivor", which is how the women in my local support group identified themselves, AA-style. For those who cease to be survivors, again, no noun applies. They are said to have "lost their battle" - our lost brave sisters, our fallen soldiers.

The cheerfulness of breast cancer culture goes beyond mere absence of anger to what looks, all too often, like a positive embrace of the disease. Writing in 2007, New York Times health columnist Jane Brody quoted bike racer and testicular cancer survivor Lance Armstrong, who said, "Cancer was the best thing that ever happened to me", and cited a woman asserting that "breast cancer has given me a new life. Breast cancer was something I needed to experience to

open my eyes to the joy of living." Betty Rollin, one of the first American women to go public with her disease, was enlisted to testify that she has "realised that the source of my happiness was, of all things, cancer - that cancer had everything to do with how good the good parts of my life were".

In the most extreme characterisation, breast cancer is not a problem at all, not even an annoyance - it is a "gift", deserving of the most heartfelt gratitude. One survivor writes in her book *The Gift Of Cancer: A Call To Awakening* that "cancer is your ticket to your real life. Cancer is your passport to the life you were truly meant to live." And if that is not enough to make you want to go out and get an injection of live cancer cells, she insists, "Cancer will lead you to God. Let me say that again. Cancer is your connection to the Divine."

The effect of all this positive thinking is to transform breast cancer into a rite of passage - not an injustice or a tragedy to rail against but a normal marker in the life cycle, like menopause or grandmotherhood. Everything in mainstream breast cancer culture serves, no doubt inadvertently, to tame and normalise the disease. Indeed, you can defy the inevitable disfigurements and come out, on the survivor side, actually prettier, sexier, more feminine. In the lore of the disease - shared with me by oncology nurses as well as by survivors - chemotherapy smoothes and tightens the skin and helps you lose weight, and when your hair comes back it will be fuller, softer, easier to control, and perhaps a surprising new colour. These may be myths, but for those willing to get with the prevailing programme, opportunities for self-improvement abound. Breast cancer is a chance for creative self-transformation - a makeover opportunity, in fact.

In this seamless world, dissent is a kind of treason. As an experiment, I posted a statement on a message board, under the subject line "Angry", briefly listing my complaints about the debilitating effects of chemotherapy, recalcitrant insurance companies, environmental carcinogens and, most daringly, "sappy pink ribbons". I received a few words of encouragement in my fight with the insurance company, which had taken the position that my biopsy was a kind of optional indulgence, but mostly a chorus of rebukes. "Suzy" wrote to tell me, "I really dislike saying you have a bad attitude towards all of this, but you do, and it's not going to help you in the least." "Mary" was a bit more tolerant, writing, "Barb, at this time in your life, it's so important to put all your energies toward a peaceful, if not happy, existence. Cancer is a rotten thing to have happen and there are no answers for any of us as to why. But to live your life, whether you have one more year or 51, in anger and bitterness is such a waste..."

Exhortations to think positively - to see the glass half full, even when it lies shattered on the floor - are not restricted to the pink ribbon culture. A few years after my treatment, I ventured out into another realm of personal calamity - the world of laid-off white-collar workers. At the networking groups, boot camps and motivational sessions available to the unemployed, I found unanimous advice to abjure anger and "negativity" in favour of an upbeat, even grateful approach to one's immediate crisis. People who had been laid off from their jobs and were spiralling down toward poverty were told to see their condition as an "opportunity" to be embraced. Here, too, the promised outcome was a kind of "cure": by being positive, a person might not only feel better during his or her job search, but actually bring it to a faster, happier conclusion.

In fact, there is no kind of problem or obstacle for which positive thinking or a positive attitude has not been proposed as a cure. Having trouble finding a mate? Nothing is more attractive to potential suitors than a positive attitude, or more repellent than a negative one. Need money? Wealth is one of the principal goals of positive thinking. There are hundreds of self-help books

expounding on how positive thinking can "attract" money - a method supposedly so reliable that you are encouraged to begin spending it now. Practical problems such as low wages and unemployment are mentioned only as potential "excuses". The real obstacle lies in your mind.

Like a perpetually flashing neon sign in the background, like an inescapable jingle, the injunction to be positive is so ubiquitous that it's impossible to identify a single source. Oprah routinely trumpets the triumph of attitude over circumstance. A Google search for "positive thinking" turns up 1.92m entries. A whole coaching industry has grown up since the mid-90s, heavily marketed on the internet, to help people improve their attitudes and hence, supposedly, their lives.

In my case, however, there was, I learned, an urgent medical reason to embrace cancer with a smile: a "positive attitude" is supposedly essential to recovery. During the months when I was undergoing chemotherapy, I encountered this assertion over and over - on websites, in books, from oncology nurses and fellow sufferers. Eight years later, it remains almost axiomatic, within the breast cancer culture, that survival hinges on "attitude". One study found 60% of women who had been treated for the disease attributing their continued survival to a "positive attitude". In articles and on websites, individuals routinely take pride in this supposedly lifesaving mental state.

"Experts" of various sorts offer a plausible-sounding explanation for the salubrious properties of cheerfulness. A recent e-zine article entitled Breast Cancer Prevention Tips - and the notion of breast cancer "prevention" should itself set off alarms, since there is no known means of prevention - for example, advises that: "A simple positive and optimistic attitude has been shown to reduce the risk of cancer. This will sound amazing to many people; however, it will suffice to explain that several medical studies have demonstrated the link between a positive attitude and an improved immune system."

You've probably read that assertion so often, in one form or another, that it glides by without a moment's thought about what the immune system is, how it might be affected by emotions and what, if anything, it could do to fight cancer. The link between the immune system, cancer, and the emotions was cobbled together somewhat imaginatively in the 70s. It had been known for some time that extreme stress could debilitate certain aspects of the immune system. Torture a lab animal long enough, as the famous stress investigator Hans Selye did in the 30s, and it becomes less healthy and resistant to disease. It was apparently a short leap, for many, to the conclusion that positive feelings might be the opposite of stress - capable of boosting the immune system and providing the key to health, whether the threat is a microbe or a tumour.

You can see the theory's appeal. First, the idea of a link between subjective feelings and the disease gave the breast cancer patient something to do. Instead of waiting passively for the treatments to kick in, she had her own work to do - on herself. At the same time, it created expanded opportunities in the cancer research and treatment industry: not only surgeons and oncologists were needed, but behavioral scientists, therapists, motivational counsellors and people willing to write exhortatory self-help books.

The dogma, however, did not survive further research. In the May 2007 issue of Psychological Bulletin, James Coyne and two co-authors published the results of a systematic review of all the literature on the supposed effects of psychotherapy on cancer. The idea was that psychotherapy, like a support group, should help the patient improve her mood and decrease her level of stress. But Coyne and his coauthors found the existing literature full of "endemic problems". "If cancer patients want psychotherapy or to be in a support group, they should be given the opportunity to

do so," Coyne said in a summary of his research. "There can be lots of emotional and social benefits. But they should not seek such experiences solely on the expectation that they are extending their lives."

It could be argued that positive thinking can't hurt, that it might even be a blessing to the sorely afflicted. Who would begrudge the optimism of a dying person who clings to the hope of a last-minute remission? Or of a bald and nauseated chemotherapy patient who imagines that the cancer experience will end up giving her a more fulfilling life? Unable to actually help cure the disease, psychologists looked for ways to increase such positive feelings about cancer. If you can't count on recovering, you should at least come to see your cancer as a positive experience.

But rather than providing emotional sustenance, the sugar-coating of cancer can exact a dreadful cost. First, it requires the denial of understandable feelings of anger and fear, all of which must be buried under a cosmetic layer of cheer. This is a great convenience for health workers and even friends of the afflicted, who might prefer fake cheer to complaining, but it is not so easy on the afflicted. One 2004 study even found, in complete contradiction to the tenets of positive thinking, that women who perceive more benefits from their cancer "tend to face a poorer quality of life - including worse mental functioning - compared with women who do not perceive benefits from their diagnoses."

Besides, it takes effort to maintain the upbeat demeanor expected by others - effort that can no longer be justified as a contribution to long-term survival. Consider the woman who wrote to Deepak Chopra that her breast cancer had spread to the bones and lungs: "Even though I follow the treatments, have come a long way in unburdening myself of toxic feelings, have forgiven everyone, changed my lifestyle to include meditation, prayer, proper diet, exercise, and supplements, the cancer keeps coming back. Am I missing a lesson here that it keeps reoccurring? I am positive I am going to beat it, yet it does get harder with each diagnosis to keep a positive attitude."

Chopra's response: "As far as I can tell, you are doing all the right things to recover. You just have to continue doing them until the cancer is gone for good. I know it is discouraging to make great progress only to have it come back again, but sometimes cancer is simply very pernicious and requires the utmost diligence and persistence to eventually overcome it."

But others in the cancer care business have begun to speak out against what one has called "the tyranny of positive thinking". When a 2004 study found no survival benefits for optimism among lung cancer patients, its lead author, Penelope Schofield, wrote: "We should question whether it is valuable to encourage optimism if it results in the patient concealing his or her distress in the misguided belief that this will afford survival benefits... If a patient feels generally pessimistic... it is important to acknowledge these feelings as valid and acceptable."

Whether repressed feelings are themselves harmful, as many psychologists claim, I'm not so sure, but without question there is a problem when positive thinking "fails" and the cancer spreads or eludes treatment. Then the patient can only blame herself: she is not being positive enough; possibly it was her negative attitude that brought on the disease in the first place.

I, at least, was saved from this additional burden by my persistent anger - which would have been even stronger if I had suspected, as I do now, that my cancer was iatrogenic, that is, caused by the medical profession. When I was diagnosed, I had been taking hormone replacement therapy for almost eight years, prescribed by doctors who avowed it would prevent heart disease, dementia,

and bone loss. Further studies revealed in 2002 that HRT increases the risk of breast cancer, and, as the number of women taking it dropped sharply in the wake of this news, so did the incidence of breast cancer. So bad science may have produced the cancer in the first place, just as the bad science of positive thinking plagued me throughout my illness.

Breast cancer, I can now report, did not make me prettier or stronger, more feminine or spiritual. What it gave me, if you want to call this a "gift", was a very personal, agonising encounter with an ideological force in American culture that I had not been aware of before - one that encourages us to deny reality, submit cheerfully to misfortune and blame only ourselves for our fate.

. Extracted from *Smile Or Die: How Positive Thinking Fooled America And The World*, by Barbara Ehrenreich, to be published by Granta on 14 January at £10.99. To order a copy for £9.99, with free UK p&p, go to theguardian.com/bookshop or call 0330 333 6846. Ehrenreich will be delivering a Sunday Sermon on Optimism at Conway Hall, London WC1 on 10 January at 11.30am. For more information, visit theschooloflife.com/sermons.

America faces an epic choice...

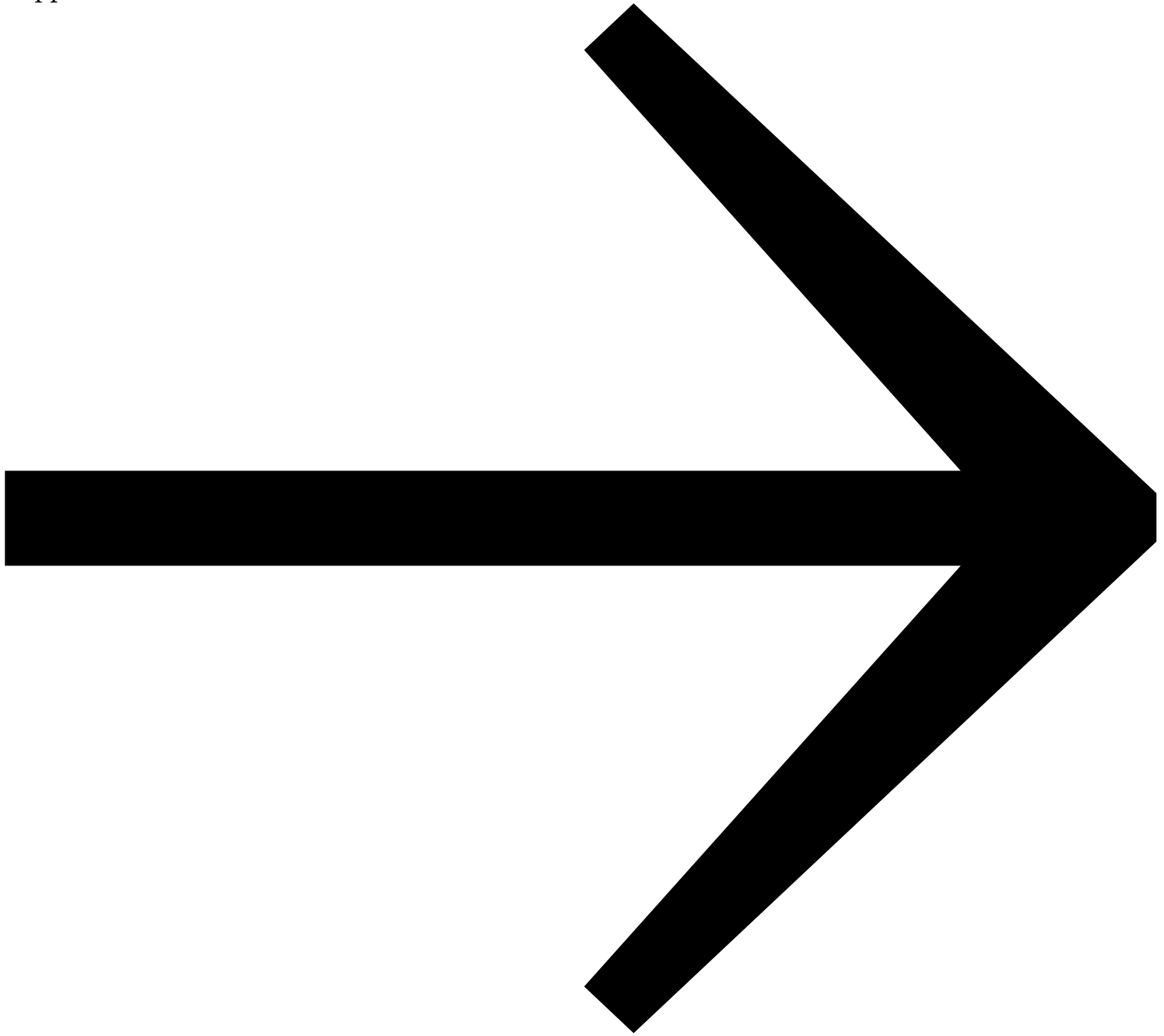
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