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Fine/Not Fine: A Cancer Intervention

by Erin Lewis

Cancer is life altering, disruptive and traumatizing no matter what kind or what stage. I'd had a lump on my neck for a year or so. I had a doctor look at it but he minimized the situation and told me a lot of people have nodules on their neck and it's nothing to worry about.

But it was something to worry about.

Fine/Not Fine: A Cancer Intervention offers a new way to think about and interact with cancer patients. The project consists of an illustrated memoir, two posters, six birthday cards and a zine, offering an autobiographical perspective by a cancer survivor. *Fine/Not Fine* helps cancer patients by educating the people in their lives. Readers learn about healthy interactions with cancer patients. They are discouraged from using toxic language, citing conspiracy theories and alleged magical cures not rooted in science when interacting with cancer patients.

Supernatural explanations and conspiracy theories about disease and its victims is not a new concept. Susan Sontag explained in *Illness as a Metaphor*, written in 1978,

“Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious. Thus, a surprisingly large number of people with cancer find themselves being shunned by relatives and friends and are the object of practices of decontamination by members of their household, as if cancer, like TB were an infectious disease.”¹

Seven centuries ago, humans did not understand infectious disease, because they did not know about microorganisms or cell biology. The Black Death swept across Europe in the 14th century, confounding explanations, understandably driving people to theorize about causes. John Albert provides a comprehensive account of *The Black Death* in his book *The Black Death, The Great Mortality of 1348-1350: A Brief History with Documents*. He delves deep into the disease explaining its geographical origins, symptoms and transmissions, medical responses and the societal and economic impact of the disease. In the chapter titled “Geographical Origins”, he explains that plague is a disease caused by the bacterium *Yersinia Pestis*. It is a zoonotic disease, meaning it is spread from animal to human. Specifically in the case of the Black Plague, from rat to flea and from flea to human. There are three different types of plague: bubonic, pneumonic and septicemic. In the cases of bubonic and septicemic, it is transmitted from flea to human. However, pneumonic plague begins in a flea and is given to a human. But then can be transmitted through respiratory droplets, meaning human to human transmission.² The knowledge of what bacteria caused the plague and how it was transmitted was unknown until 1898 when it was discovered by Jean Paul Simond.

2 Aberth, John. 2005. *The Black Death: The Great Mortality of 1348-1350*. Bedford/St. Martin's, 2-25

1 Sontag, Susan. 2013. *Illness as Metaphor and AIDS and Its Metaphors*. Penguin UK, 6

Cures for the plague, prescribed by priests, varied from blood letting to submerging oneself in a hot bath. Laypeople came up with their own ideas on how to cure the disease and how it spread. Many Christians in 1346 believed Jews to be the cause of the plague. They imagined that Jews were poisoning the drinking water or conspiring with lepers to infect Christians with the plague. Because of this, Jews were murdered by the thousands by being burned alive. Some were murdered as a precautionary measure.³

Another common practice was flagellation. The disease was imagined to have a spiritual cause, rooted in sin. Pious Catholics thought God was punishing them. They recognized the disease as an affliction of the body, and believed the disease could be warded off by repenting.⁴

³ Ibid., 64-96

⁴ Ibid., 117-122

Right

Scene of Self-Flagellation, from the Nuremberg Chronicle. Artist: Michael Wolgemut. Woodcut, 8.1 x 10 cm
Source: Achenbach Foundation for Graphic Arts.

Right

The Burning of the Jews (Schedels Weltchronik). Artist: Michael Wolgemut. Woodcut
Source: Center for Jewish History



Das sechst alter



Das ellend iamerig vñ trost-
lose volck der iude hat nach
der gepurt cristi. M. cc. xxxvij. iar
zu Deckendorff an der thonaw im
bayerland zuuerschmehung vñnd
belachung der götlichen mayestat
vñnd hohwürdigkeit desselben vn-
sers herren Ihesu cristi vñnd vnser
heiligen cristenlichen glawbens.
das allerhailigst sacrament vñfel-
tiglich gestochen. danach in einen
gländen ofen gelegt. vñnd zu lest
als er vnuerfert blibe auff eim an-
pays mit hemern geschlagen. Als
aber auß götlichem willen solchs
offenbar wardt do warden die iu-
den von Hartman von degenberg
dem pfleger vñnd den burgern da
selbst angenommen vñnd auf ersarig
der warheit mit gepürlicher peen
des tods telfrafft. vñnd dieselb ho-



Above
Representation of a massacre of the
Jews in 1349 *Antiquitates Flandriae*,
manuscript 1376/77
Source: Royal Library of Belgium



Masque

Edgar Allen Poe's *The Masque of the Red Death*, published in 1842 was inspired by first hand accounts of the Black Death. The short story depicts a gruesome plague that is ravaging a village. But the Prince of this village is hopeful and uses his privilege and power to throw a party in his elaborately decorated palace. There are seven rooms in the palace that each have their own hue. The last and most ominous room is decorated in black with a large obnoxious clock that stuns the party goers when it chimes. The party goers have convinced themselves that they have eluded death but when the clock strikes, a reminder of their mortality and fragility shatters them to their core for just a moment. When the clock strikes midnight, the party goers notice an unusual guest dressed as Death itself. The Prince, horrified and offended, immediately orders his arrest. But no one is brave enough to touch the figure. Ignoring the Prince, Death begins walking from room to room stopping in the final black room.

“Prince Prospero, maddened with rage and the shame of his own momentary cowardice, rushed hurriedly through the six chambers, while none followed him on account of a deadly terror that had seized upon all. He bore aloft a drawn dagger, and had approached, in rapid impetuosity, to within three or four feet of the retreating figure, when the latter, having attained the extremity of the velvet apartment, turned suddenly and confronted his pursuer. There was a sharp cry—and the dagger dropped gleaming upon the sable carpet, upon which most instantly afterward, fell prostrate in death the Prince Prospero. Then summoning the wild courage of despair, a throng of the revellers at once threw themselves into the black apartment, and seizing the mummer whose tall figure stood erect and motionless within the shadow of the ebony clock, gasped in unutterable horror at finding the grave cerements and corpse-like mask, which they handled with so violent a rudeness, untenanted by any tangible form. And now was acknowledged the presence of the Red Death. He had come like a thief in the night. And one by one dropped the revellers in the blood-bedewed halls of their revel, and died each in the despairing posture of his fall. And the life of the ebony clock went out with that of the last of the gay. And the flames of the tripods expired. And Darkness and Decay and the Red Death held illimitable dominion over all.”⁵

5 Poe, Edgar Allan, Basil Rathbone, and Howard Sackler. 1988. *The masque of the red death, and other poems and tales of Edgar Allan Poe*. New York, NY: Caedmon.

Right

The Dagger Dropped Gleaming Upon the Sable Carpet,” by Harry Clarke, 1919. Illustration from Edgar Allan Poe's *Tales of Mystery and Imagination*.

Source: NC State Special Collections Library

of the



Red Death

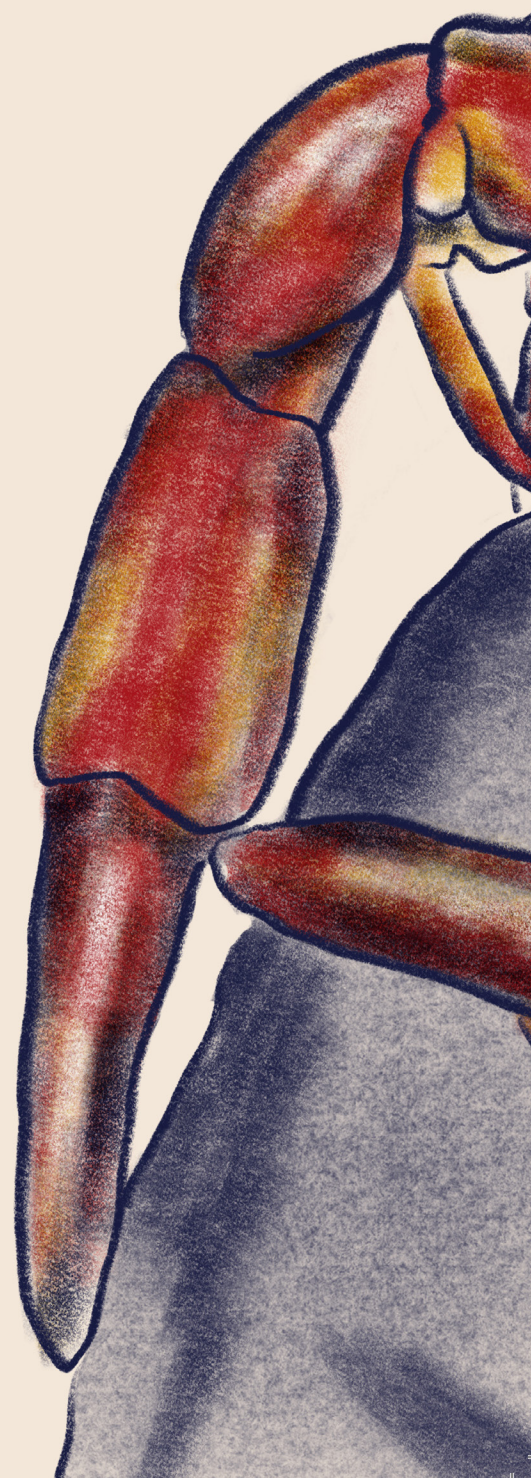
As frightening as the Black Death was, infectious diseases have since been domesticated by germ theory. The pandemic of today--our Black Death--COVID-19 can be readily explained. By contrast, cancer is harder to grasp. The disease begins when cells in a part of the body are given the wrong information and like the game of telephone, begin multiplying and grow out of control. The word cancer is of Greek origin, named by Hippocrates in 460-370 BCE "most likely applied to the disease because the finger-like spreading projections from a cancer called to mind the shape of a crab."⁶ The name itself refers to the manner in which a tumor behaves. It spreads.

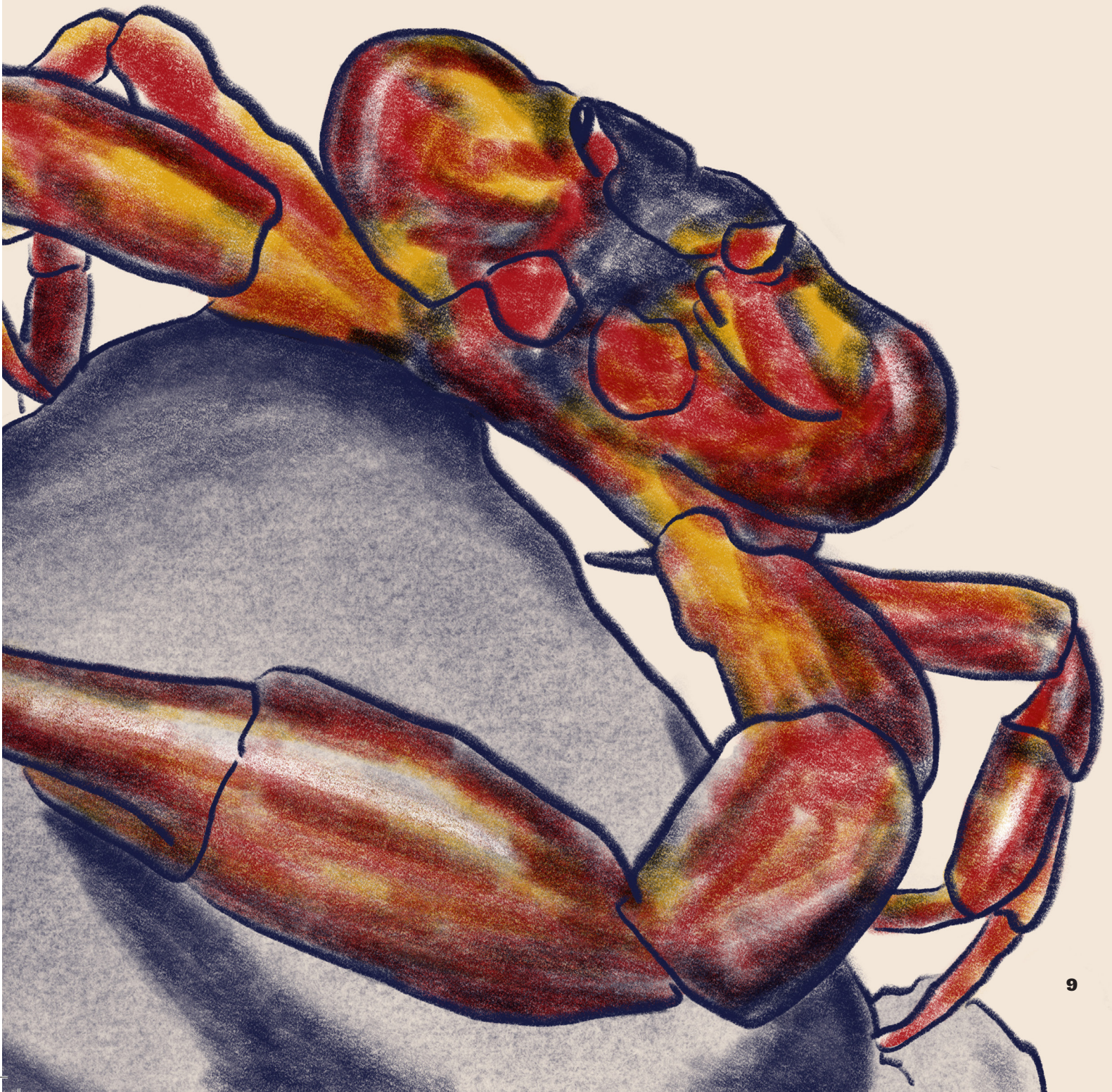
"Ancient physicians and surgeons knew that cancer would usually come back after it was surgically removed. The Roman physician Celsus wrote, 'After excision, even when a scar has formed, none the less the disease has returned.' Galen was a 2nd-century Greek doctor whose books were preserved for centuries. Galen viewed cancer much as Hippocrates had, and considered the patient incurable after a diagnosis of cancer had been made. His views set the pattern for cancer management for centuries. Even though medicine progressed and flourished in some ancient civilizations, there was little progress in cancer treatment. The approach to cancer was Hippocratic (or Galenic) for the most part. To some extent the belief that cancer cannot be cured has persisted even into the 21st century. This has served to fuel the fear people have of the disease. Some people, even today, consider all cancer incurable and put off seeing a doctor until it's too late for optimal treatment."⁷

6 "Early History of Cancer | American Cancer Society." n.d. American Cancer Society | Information and Resources about for Cancer: Breast, Colon, Lung, Prostate, Skin. Accessed April 5, 2021. <https://www.cancer.org/cancer/cancer-basics/history-of-cancer/what-is-cancer.html>.

7 Ibid.

Right
Illustration from *Pretending to be Happy* by Erin Lewis









walking reminder

Erin Lewis

Just as the Black Death mystified 14th century Europeans, and Poe's Red Death overwhelms his revelers, cancer bedevils contemporary people. Today in 2021, we know more about cancer due to advancements in genetic testing, imaging technology, chemotherapy and radiation. People know cancer is not contagious but their behavior suggests they are fearful when interacting with cancer patients much like people in the 14th century when dealing with plague patients.

While cancer treatment has improved since Susan Sontag's *Illness as Metaphor*, beliefs about cancer remain contradictory and problematic. A quantitative study of public perceptions in 2014 found that people feel "a rapid, intuitive sense of dread and imminent death coexists with a deliberative, rational recognition that cancer can be a manageable, or even curable, disease."⁸ Sontag provides historical evidence to help us understand why cancer is still so taboo. She argues that people are simply afraid of death and don't know how to talk about it.

"As death is now an offensively meaningless event, so that disease widely considered a synonym for death is experienced as something to hide. The policy of equivocating about the nature of their disease with cancer patients reflects the conviction that dying people are best spared the news that they are dying, and that the good death is the sudden one, best of all if it happens while we're unconscious or asleep. Yet the modern denial of death does not explain the extent of the lying and the wish to be lied to; it does not touch the deepest dread."⁹

For centuries, cancer was a death sentence. Depending on the staging and type, certain cancers remain a death sentence today. But death is no longer certain for everyone who is diagnosed. Even so, cancer turns a person into a walking reminder of the impermanence of human life.

Disease can happen to anyone and that is a scary thought. "The disease, often discovered by chance or through a routine medical checkup, can be far advanced without exhibiting any appreciable symptoms."¹⁰ Sontag explains that cancer can infect any part of the body and anytime a patient tells someone they have cancer, they have to communicate which part of their body is

affected. Places like the breasts, prostate, colon, ect. are uncomfortable and shameful to talk about. It is easier for patients to hide in the shadows with their disease rather than explain to others the ways in which their body is malfunctioning. Patients often have to defend the ways they have treated their body. Partly informed by science, and partly fed by superstition, patients are subject to questions like:

"Well how often do you exercise?"

"Do you drink green tea?"

"Did you eat processed foods growing up?"

People like to believe that they can do everything right to avoid getting cancer. Implicitly a cancer patient must have done something wrong somewhere down the line. Such ideas perpetuate shame.

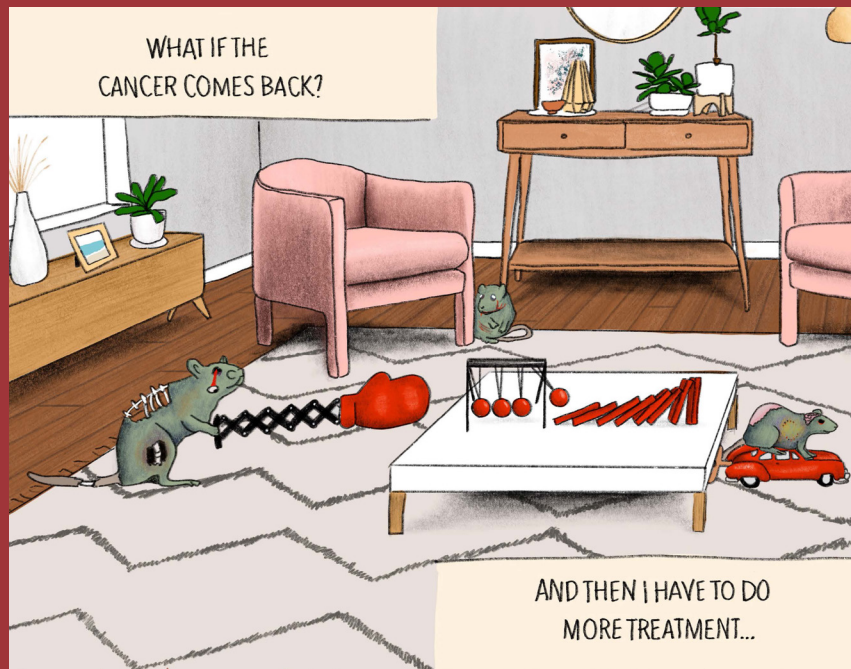
of the

impermanence

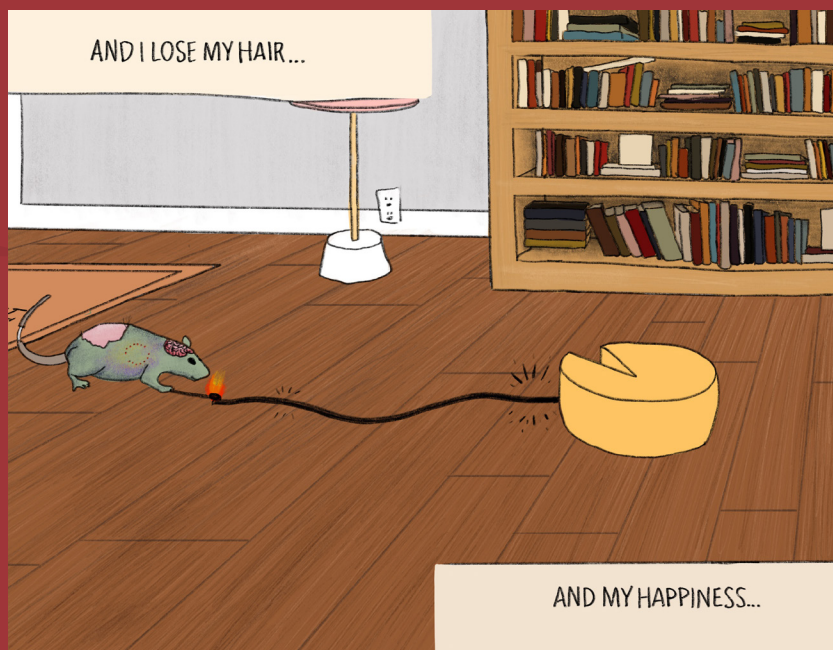
8 Robb KA, Simon AE, Miles A, et al. Public perceptions of cancer: a qualitative study of the balance of positive and negative beliefs. *BMJ Open* 2014

9 Sontag, Susan. 2013. *Illness as Metaphor and AIDS and Its Metaphors*. Penguin UK, 8

10 *Ibid.*, 12



Above and below
Illustration from *I HAVE A SCAN TOMORROW* by Erin Lewis



I DON'T WANT TO



DEAL WITH THIS

“Cancer is understood as the overwhelming or obliterating of consciousness. In cancer, non-intelligent cells are multiplying, and you are being replaced by the non-you. Immunologists class the body’s cancer cells as “nonself.”¹¹ If you are becoming something else, being replaced by something else, people can’t help but feel as if there is an entity in the room. Add on the additional metaphor that this entity can snatch and grab you at any moment, fear is a natural response.

When confronted by fear, many people react with the instinctual fight, flight, freeze or fawn. As noted, people can often feel a twinge of fear when they learn a friend or loved one has cancer. An overwhelming number of patients experience being fawned over. Another term for this is toxic positivity.

The term toxic positivity has gained steam in the last several years, becoming increasingly popular in the year 2020. When life was very difficult for many people, it became unbearable to interact with people who only wanted to see “the good”. A study conducted in 2008 by John B. Nezlek and Peter Kuppens concluded that suppressing negative emotions can be far more harmful than experiencing the negative emotion. “Our data suggest that, at least on a daily basis, people’s affective experience is (at most) only weakly related to, and is certainly not improved by, suppressing negative feelings. If anything, attempts to suppress the expression of negative emotions are associated with increases in deactive negative emotions.”¹²

11 Ibid., 67

12 Nezlek, John B., and Peter Kuppens. 2008. “Regulating Positive and Negative Emotions in Daily Life.” *Journal of Personality*, no. 3 (June): 561–80. <https://doi.org/10.1111/j.1467-6494.2008.00496.x>.

When thinking about toxic positivity and cancer, one group of individuals comes to mind as the most egregiously affected, and that is breast cancer patients. The breast cancer ribbon was created by a 68 year old woman named Charlotte Haley. She saw the awareness the AIDS campaign was getting and borrowed a page from their book and used a ribbon. It was salmon colored and she attached it to a card demanding the National Cancer Institute to invest more of their enormous budget into breast cancer prevention. *Self Magazine* then called Haley wanting to partner with her on her endeavors. Haley refused, stating *Self* was too commercial and would be looking out for themselves. The lawyers at *Self* came up with a sly plan to simply change the color of the ribbon so they were not “stealing” anything from Haley and thus the Pink Ribbon was launched.¹³

The highly feminized campaign portrays breast cancer in a positive light. The logo is cute with an innocent ballet slipper pink color. The entire month of October is dedicated to breast cancer where professional athletes sport the color pink on their jerseys in support of those “battling” the disease. A vast array of companies from cosmetic to tech pump out pink colored products in hopes to boost sales and in turn (sometimes) donate a portion to breast cancer research. The race for the cure sponsored by Susan B. Komen attracts hundreds of thousands of people who dress up in costumes, dance to upbeat music and cheer loudly for their fallen friends. All of these cases of the pink ribbon are associated with words like cute and fun.



13 Fernandez, Sandt. “History of the Pink Ribbon.” Think Before You Pink, July 1998. <https://thinkbeforeyoupink.org/resources/history-of-the-pink-ribbon/>.



Above and right
Screenshots from *Pink Ribbon Inc.*



Pink Ribbon Inc. is a documentary about the Pink Ribbon campaign and the ripple effect it's had on various groups of people and corporations.¹⁴ The director, Lea Pool, opens the documentary with a series of images from the Susan G Komen Race for the cure. Women dance, smile and “celebrate life” all the while trotting along with race tags attached to their shirts.

These images are then juxtaposed with conversations with breast cancer patients. Barbara Brenner, a breast cancer activist, begins the string of oppositional interviews by saying, “Many people say anger is not helpful. Actually anger is helpful. Depending on what you do with it. And I think if people actually knew what was happening, they would be really pissed off. They should be.” The documentary switches to a breast cancer support group in Austin, Texas. The women in the support group are huddled together, everyone lightly touching one another with a certain quietude about them.¹⁵

Jeneane Collins described the isolating feeling of being different from other cancer patients. “You go to a ‘regular’ breast cancer support group and you’re the angel of death—the elephant in the room. They are learning to live and you are learning to die.” Even cancer patients, who have experienced thoughts of mortality and death, find it difficult to interact with someone who is dying.

Maricela Ochoa tries to give people the benefit of the doubt while also expressing her need to be seen and heard. “I know many people probably have good intentions when it comes to the pink ribbon. But that’s all they’re seeing. I want them to see the people that are hurting. And people that are living with stage IV Breast Cancer. We are human beings. We’re not just a little pink ribbon.”

Susan Kugleman describes how harmful the military messaging of fighting can be. “The message is that if you try hard enough—you put forth the effort—if you just do it—if

you live strong—you can beat it. You can. You can do it. So just try really hard. And the problem with that message is you can’t have that and then not see the people who die as somehow not having lost. They ‘lost their battle’ because why? They didn’t try hard enough. I don’t know that people really think that through. But it’s a very clear message that we (patients) are very aware of. So for someone, the most fragile and vulnerable people in the cancer community—to be faced with that kind of painful messaging...it’s wrong. It’s just wrong.”¹⁶

Barbara Ehrenreich, an author and activist, explained her first encounter with the pink ribbon while she was in the waiting room of a doctor’s office. “I was looking at the local classifieds and there at the bottom was a pink breast cancer teddy bear. I can’t tell you how much it offended my sense of dignity. There I was, a middle aged woman, facing the most serious health crisis of my life—facing my own mortality—and someone’s offering me a pink teddy bear? I’m sorry but I’m not 6 years old.”

Sprinkled between the interviews with patients are interviews with Nancy Brinker, CEO of the Susan G Komen foundation. These are her thoughts on the Pink Ribbon movement. “In response to the question if we are putting a pretty pink face on this—we absolutely categorically are not. Because when you lead from only anger, you do not include or incent people to be part of a mission. If people feel there is no hope they will not participate long term. They will feel they are in an endless fight.”¹⁷

To end this critical documentary, Barbara Brenner asks the public for help in ending the fake positivity and pink distracting by calling for action. “I do think the public has enormous power if they would just use it.”¹⁸

¹⁴ Ibid.

¹⁵ Ibid.

¹⁶ Ibid.

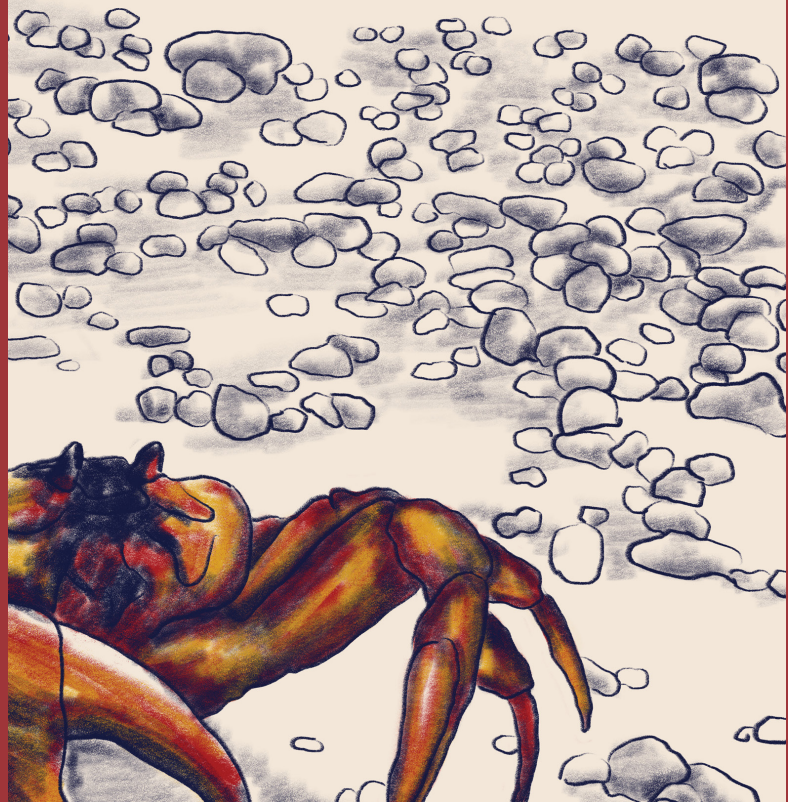
¹⁷ Ibid.

¹⁸ Ibid.

Erin Lewis

Pretending to be Happy

Erin Lewis



Above and right

Cover and interior pages from
Pretending to be Happy by Erin
Lewis
5.25 x 8.5 in

The heart of *Fine/Not Fine* is a twenty-eight page illustrated memoir titled *Pretending to be Happy*. The first person narrator details the trauma experienced as a result of the physical repercussions of having cancer. She also expresses the trauma inflicted by non-cancer patients. Throughout the memoir she expresses how she pretended to be happy for the sake of others but at her own detriment. The memoir follows her story as she rehashes the events that took place and how she eventually found her voice.



I have a bad habit of looking at old photos and categorizing them: before and after.

I look so innocent in photos from before. I look at them and think, "Girl, you don't even know what's coming."

I had that "life is easy" glow.

I have very few pictures from in between. Not before. Not after. But during. Those pictures were deleted in a meltdown.

In the same way you spring clean your house, I tried to spring clean my phone of all the cancer.

I have always struggled with body image.

Having cancer certainly did not help this struggle. My body, that I already did not have a great relationship to begin with, turned against me and tried to kill me. I felt so divided from my body.

**Enemies
being forced
to share
the same
space.**

I have scars.

People would ask:
"What's that on your neck?"

Without knowing they were pointing out a very vulnerable part of me. People still do that from time to time. I wish people would stop talking about my body unless I bring it up myself.

Unless it's complimenting my butt.



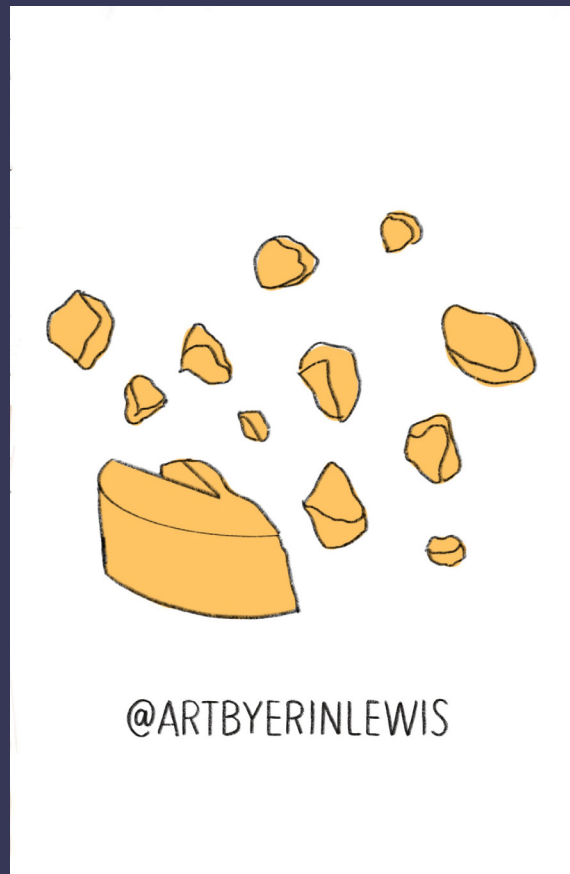
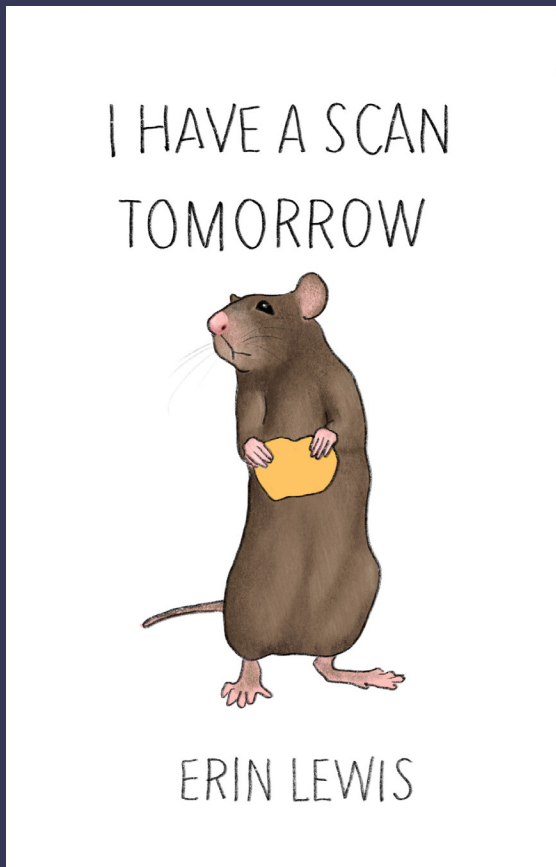
Above
I DON'T WANT TO DEAL WITH THIS, poster by Erin Lewis
Digital print, 18 X 24 in

The comic poster titled, *I DON'T WANT TO DEAL WITH THIS*, deals with the same toxic positivity that is captured in *Pink Ribbon Inc*. The comic depicts a young adult waiting to meet a friend in the park. While she is waiting she experiences several uncomfortable situations of toxic positivity. Each time she is confronted with a toxic person, she politely goes along with what they are saying even though she is very bothered. The audience is privy to her inner thoughts, while the toxic characters are not.



Above
Birthday card by Erin Lewis
Digital print, 5 X 7 in

The birthday cards illuminate the idea that not everyone is happy on their birthday; especially those struggling with thoughts of mortality. Though the cards are made to inspire a laugh, they also hit hard on the fact that acknowledging hard days can be powerful. In *Pretending to be Happy*, the narrator shares how difficult her birthday was during cancer treatment. On her birthday she was given flowers and a card that acknowledged her sadness and was a transformative moment for her. Inspired by that moment, the birthday cards allow people to feel sad when they are told by so many to feel happy.



Above
Cover and back cover
design from *I HAVE A SCAN
TOMORROW* by Erin Lewis
Digital print, 5 X 7 in

SOMEONE JUST SAID

I have cancer.

WHAT DO I SAY?

FIRST

I'm so sorry this is happening to you.

NEXT

IS THIS PERSON YOUR FRIEND?

YES

I love you and I am here for you.

NO

Quit while you're ahead. Go away now.

THEN

IS YOUR FRIEND A TYPE A PERSONALITY?

YES

Can I come over to clean your kitchen and do laundry?

NO

Can I come over to watch romantic comedies with you?

AFTER THAT

DOES YOUR FRIEND LIKE DARK HUMOR?

YES

Do me a favor and don't die before Christmas. You give the best gifts.

NO

What you're going through is really hard and it sucks.

FINALLY

Give space for sadness. Your friend will need to say some sad things and you just need to listen.

DONT EVER SAY...

I know how you feel.

My cousin's friend's teacher had that. She died.

You're a warrior! You got this!

The second poster, titled *SOMEONE JUST TOLD ME “I have cancer.” WHAT DO I SAY?* is a flow chart that details how a conversation might go with a cancer patient. The poster asks the audience questions and lets them navigate the poster accordingly. It gives the audience specific examples and prompts to assist in interacting with a cancer patient.

Lastly, the zine titled, *I HAVE A SCAN TOMORROW* illuminates the spiraling thoughts cancer patients experience when it is time for a scan. The patient’s fears are often minimized, making them feel crazy for entertaining the idea of bad news. Even though bad news is a very real possibility. The more patients silently stew about bad news, the larger the fears grow.

The project is all wrapped up together in an orientation style kit as if to say, “Welcome to Cancerland, please be kind to the residents.” Each item in the piece plays a vital role in helping cancer patients feel normal and less isolated. *Fine/Not Fine* needs to be in the hands of friends and loved ones of cancer patients. It would be a great addition to support groups and companies like the American Red Cross who can distribute the contents to those who need it.

Right

SOMEONE JUST SAID, I have cancer. WHAT DO I SAY?, poster by Erin Lewis
Digital print, 12 X 18 in

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