



The Cancer of Fibropoetics

Jane Joritz-Nakagawa

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The Cancer of Fibropoetics

Nightmares and daydreams

I am in the shower, in the middle of a brightly lit store with a front wall that is all glass. There are no items on the shelves. The shower curtain is transparent. I am wearing my colostomy and urostomy bags. A group of people I know are down the street. They are coming my way! I can see them coming closer and closer. I don't care about them seeing my naked body, I only care -- I very much care -- about them seeing my ostomy bags (even though these are either empty or opaque in the dream; I normally wear clear ones). They see me and start calling my name! What to do? There is a towel but it is small and outside the shower booth. I try unsuccessfully to hide my bags with my hands.

I imagine that I am on a train and my colostomy bag starts leaking. It is summer and I am wearing only a white tee shirt and short pale grey flare skirt. Everybody can see the brown liquid oozing over the waistband of my skirt. I try to get a towel out of my bag but the liquid keeps oozing down to the hem of my skirt before I am able to find the towel. Too late! Some people are staring and others are looking away horrified.

In a variation on the above I am in a public bathroom doing an emergency change of ostomy bags not in the privacy of the toilet stall but in the common sink area where I have access to running water and soap. I have pulled down my skirt and pulled up my tee shirt. I am carefully cleaning around the two stoma as I was taught to do in the hospital. Women are entering and exiting the bathroom. Some look at me with an angry expression and others with a disgusted one. Everybody tries to avoid the sinks that are close by, going to a far corner of the room to wash their hands in order to not be near me. Some leave as quickly as possible, almost running out of the room, once they see me.

I am an action figure but my life is very hard as I must constantly defend myself from other action figures who are more powerful than me or manage to evade them. But one day I enter an underworld paradise full of women (including Angela Davis, Audre Lorde and Gloria Steinem) who lounge on lily pads, eat grapes and talk about feminism. I hide out in this dark but comforting water world for as long as I can. My action figure clothes dissolve and become a white flowing robe with a golden silk cord; my military style boots become the sandals of Jesus. I find peace here as long as I can.

Dogs can poo on the street, why can't I?

Fibromyalgia

I need to walk every day to keep the pain away or at bay. A friend suggests that when I walk, I only do walking and don't for example combine it with a trip to the supermarket. And that I try to walk fast, although that actually is impossible for me I think.

Today it is cold so I put on my brown fleece skirt, black Vneck, grey fleece turtleneck,

and long black acrylic scarf. I walk aimlessly, avoiding the supermarket and the drugstore. I walk in circles. I get lost in thought and almost feel like I have gotten lost in the neighborhood. I am near a small stream. I see a swan! I am very excited. But when I get closer it's just a white plastic bag with garbage in it floating on the water. Later I really do see a swan but it flies away when it sees me.

*Mild adversity
in the wind (Iijima, 2004)*

Cancer

Did I like my body before cancer? Does any woman like her body? I have met the most beautiful women who claimed to find fault with their bodies. I never thought of my body as that beautiful although I thought maybe I had a few good features, but these no longer exist.

*Little paper girls of various colors are falling from the sky. [. . .]
Only the gold ones speak, but there are no more of those around
here (Pizarnik, 2013)*

Maybe I didn't love my body enough.

I remember a friend who said she wanted to dare herself to never shower, dress badly and wear makeup in a way that made her less attractive.

I used to have (before my weight loss from cancer) what one lover called affectionately a bubble butt. I remember a girlfriend in college who claimed that before I sat down on a bar stool I stuck my ass up in the air as far as possible to make it more noticeable to men. She also claimed our other girlfriend (we went clubbing as a gang of three) swung her breasts into men's elbows as she talked to them in the bar.

Now you can eat whatever you want a friend who wants to encourage me to gain weight says to me. I've always eaten what I've wanted.

I have learned to adapt to many things. I learned to love myself after growing up not loving myself. I learned to overcome or compensate for many weaknesses I found in myself after becoming a teacher although not perfectly, I still have flaws of course. Moving to Japan from the U.S.A. was both easy and difficult. I had to overcome "automatic" responses that seemed to be "second nature" but that wouldn't be tolerated here. I learned. It was a thrilling process. It never ends in a way. So much to learn. It's humbling. Every day I speak Japanese with a thick American accent. I make mistakes. As I age, I forget things. I don't miss the violence I faced in the U.S.

I can adapt to this. I love my body. Even if it took several months before I could use two mirrors to look at my new backside. It took a long time before I could try only to simply crane my neck around to see myself from behind but I couldn't see anything. I've only

recently gotten over the shock of seeing myself from the front. Or actually, maybe I am not over it. It feels like there is a marshmallow back there.

I walk outside today wearing the same clothes as yesterday. I see a woman staring at the bandage on my right leg and realize I have an urge to hit her with my handbag.

Today was ostomy bag-changing day. It's the day where I feel clean. For a few minutes, while sitting on a white plastic stool in the shower room, cleaning around both of my stoma as carefully as possible, I get to just be me in my own body, with nothing plastic hanging onto me. But it is also the day I am nervous. I may make a mistake when changing the bags.

I love my body even though it is pitiful.
I love my body because it is pitiful.

(I know part of this attitude is pitiful.)

My body is pretty. My body is ugly. My body is pretty ugly. My body is ugly pretty. It is pitifully beautiful / beautifully pitiful. A pitfall.

A crying shame how no one speaks the language anymore
(Berkson, 2014)

The great pretender

Not long after surgery when I venture out of the house I feel like a total fake. As I get dressed and hide everything under my clothes, it seems wrong to go out like this, with everything hidden. Sometimes I feel like pulling my clothes off and shouting "Hey! Everybody! Look at this!"

I think of Freddie Mercury singing *The Great Pretender* and *I'm Going Slightly Mad*.

Not long after this X and I see *Bohemian Rhapsody*. Queen fills my head for days afterward

I go shopping for clothes that drape well, that hide my ostomy bags.

Talk therapy

My inner cancer patient talks with my fibro patient:

C: What's wrong with you today?

F: Oh, my body is so achy, it's driving me nuts. It's hard to concentrate. I don't feel like seeing anybody. I don't think I could be much of a conversation partner. I'm so stiff I feel like I'll tear something just by moving an inch or two.

C: Well at least you're not me. Hey, why don't you do something about it?

F: Do something about it? I am already taking medicine. Don't you know a lot of this is your fault? I used to take a bath every morning followed by gentle stretching/yoga, calisthenics (focusing on the stomach, back, hips and thighs especially) and a walk. This really helped a lot! But the stoma nurse told me not to take baths because they will loosen the seal of the ostomy flanges. Bathing was the only way I felt I could stretch safely -- otherwise I am so stiff stretching hurts me. I'm walking but it doesn't seem to be enough. My body is like a wooden board. And I stopped doing weights because I am afraid of getting a stomal hernia. I am too thin and I have tried to gain weight. I've failed. And my skin itches. My stomach hurts.

C: Your complaining is starting to bore me.

F: I'm sorry, but you asked what was wrong with me.

C: Are you still reading Trakl and Dickinson?

F: I had stopped but recently yes a little bit.

C: What else are you reading?

F: I have resumed reading *There there* but--

C: It's a dark book. How about your intimate life?

F: Oh please you know better than to ask me about that!

C: Somebody should write a sex manual for people with ostomies and who also have no

F: Enough already! You've gone too far this time!

C: Sorry. How is *There there*?

F: It's interesting but sad. There is this chapter where one of the characters . . .

C: Which one?

F: I don't remember, it's on my Kindle, actually my Kindle is now broken but, in any case, she notices a person who walks into a restroom is elderly by virtue of the fact that her shoes have velcro.

C: So what?

F: My shoes have velcro.

C: That's because of me, right?

F: Yes.

Created both sides in each of you (Notley, 1995)

Dreamland

We are constantly trying to evade a group of armed men. I travel up and down small curving grey rocky mountain paths to a large wooden house where members of our group are being held at gunpoint in the kitchen and living room. Someone whispers to me: *You have to find the intersex girl. She holds the key to the magic box. If you find her this will be over.* I return to the mountains to look for her. I feel desperate, and incompetent. And then wonder if she is me. Although I am not intersex. Because my body has been radically altered.

In another dream fabrics are attached to people like limbs and I have to try to make different ones to suit them. Mostly they are blue white and red Japanese designs. This is very difficult.

I must make something pretty to combat the ugliness:

duet of flowers
chosen for hue

duty of grass

duly noted

the truth is prettier than that

the amount of rest the ill need

tendrils

stomach aloft

missing piece

wept

in her steep of

To flaunt

a smile

blinkering

the foot to

open, the night

how to order

ease of shipment

minute blasphemy

packed at

wonder

of specimens

combat felt

of native cross

new aridity

falls silent

awake at

leaning for example

a mind

in mind

encumbered

flossy

in a hush

words to the touch

splash

alert

vanquished

at last

city

churning

in time

sampling

a body

fallen

flung

consumed identity

as inkling

ruined map

lakefront restaurant

valley was i

social grid

detonated

pale blue

lifelong fabric

worn

aimed at

filter

some shavings

proof

aloft

) therein

I distract myself by reading poems: *Everyone's / reeling from having too much feeling, / a burden and a prize* (Hoover, 2018).

Another day 1

Y. has died. I had wanted to go with X. to the hospital but reluctantly went instead, as promised, to deliver a guest lecture in an American culture class at a private Japanese university. The next day I fall down in the *genkan* of our house and remember the day after my mother died, how I passed out leaving the shower room. I find blood in my underwear the next day. I don't know if it is from the fall or not. While walking to the supermarket many times I bend over in pain, hardly able to continue. I reach the supermarket and sit down in the arcade area where a schoolgirl in another chair is looking at her mobile phone. I take narcotic medicine that I have in my bag. I am barely able to shop and walk home. In the *genkan* of our house I pause. I want to cry tears of relief. I feel comforted by the walls of the house. Z. was supposed to have been with me today. I feel lonely but also a little bit lucky that I was able to sleep more and have time alone today:

a return to the silence / of silence [. . .] when everything else / is but longing--
(Seidenberg 2014)

Before words can run out, something in the heart must die (Pizarnik, 2013)

Another day 2

I am reading poetry on the train (*weak interpretations, / out of keeping / with inklings / of continual life, / bother my anecdotes*: Brown, 2015) and almost have to read aloud (mouth the words silently) to calm myself down. I am on the way to meet friends. Ordinarily I look forward to meeting friends but since my surgery I have frequently found many social interactions very difficult. Especially if the topic of health comes up. I feel desperate to avoid that topic. I can't listen to people talk about their own health. I don't want to answer questions about mine. Meeting new people and small talk seems impossible. I listen but I stare at my lap. I feel angry and sad.

Another day 3

The inside was painful. The outside, too. I couldn't speak to my doctors or friends. I spoke to myself every night, always the same conversation, lying on my back looking at the ceiling until I became bored with the dialogue and took medicine to knock me

out.

Writing emails but not sending them. Being operated on but not cured. Being cured but not happy about it. Happy when distracted. Happy with nausea. Happy with pain. Fearful when unconscious or conscious. Anxious and depressed. *every prick and twinge* (Seidenberg, 2017) every jar bump and lightning bolt. Living in the land of the living and almost dead, living between those worlds, living in the overlap. Living in the fittings. Living in the space between. Living when allowed.

an ideal decay, the final hostage . . . (Seidenberg, 2017)

To perform everyday tasks. To not resent it. To not be angry. To find something in common. With physical and emotional cripples. Crip is hip. To not listen to news of dismembered journalists. To not hear news of young girls abused by their fathers. To forget the murder of women. The problems of migrants. Practicing road rage with invisible cars. To identify every tragedy. Missed opportunities. To seem normal but not. Not caring about how one looks today or tomorrow. To stop. To bend over double and backwards. To be bullied. To be an object of ridicule. To dream the future is better than the past and present. To give up. To acquiesce.

As if trying truly to soothe (Notley, 1995)





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Biographical Information

Jane Joritz-Nakagawa's most recent poetry books are <<*terrain grammar*>> (theenk Books, 2018) and *Poems: New and Selected* (Isobar, 2018). Email is welcome at: janejoritznakagawa(at)gmail(dot)com.

Marcus Grandon is a founding member of *Imagikon*, a group of visual artists based in Shizuoka City, Japan. He is always interested in collaboration. Contact him at: marcusgrandon@mac.com.