

Disease as an aesthetic project

Spirula and the Thing

When something intimately changes your body, your possibilities to move, your dynamic with the outer world, your identity for many people, your limits as to what you can bear, that thing forces you into inner transformation. I hate the thing, I love the thing. The thing forces me over my edges, I cannot squeeze it out of me, I cannot directly influence it, I can only take it as a challenge to my rational mind, to what I have been, to my own limitations. It has grown more than I have ever thought it could. It became big and ugly and part of me. I have to live and love myself with my monster. It is a visual enormity. I am to myself a visual enormity. I prefer to close my eyes.

This is not anymore a social game, it's within me. It forces me to be real, to be like an unwanted Star Trek character. To walk like an animal. To walk slowly, like an animal. To transform my showers into psychological thresholds. To be deformed, asymmetrical, slow and clumsy, to eat in bed. To stay in bed. To not move, to stay only on one side, in bed, to struggle to turn. It pulls me to the ground, my leg heavy with it in it. My left leg doubled, tripled and more. I am a monster. I am a visual enormity. I breath, I live, and I sometimes go through space.

It often feels that the struggle is not with a disease but between the huge thing on my left thigh and my mind. It plays with the limits of what I can bear myself to be. What have I become? How did I transform? It keeps me from moving freely. It numbs my hopes, it freezes my imagination. I can just be more free inside to allow myself to dare the impossible. Every time I am embodying a virtual walk through a forest I am calling the impossible. To toy with the possible so that without you noticing you are doing the impossible. It makes me find ways to keep myself from judging myself the moment I step over the border. I need to distract myself exactly the moment I step into the fantastical. If I succeed the fantastical is normal and real. And I can maybe walk a little bit faster.

I cry, I shout, I refuse to live in fear. I collapse with fever, fear has overtaken me, the thing laughs at my weakness. I am still here. I wake up in the night, I get up and sit on the side of the bed. It's hard to sit. I am too asymmetrical. I despair. I refuse to live in fear. I want the thing to disappear, to stop harassing me. I have no break from it. I have no break from me. Who am I? I dreamed I was wearing the nicest, most pleasant and comfortable outfit and when I looked into the mirror, a monster head showed itself under my beautiful hoodie. I prayed to be delivered from this deformity but while praying my face kept changing, monstrous. Form didn't want to settle on my face. I was surface, without stability. It's past midnight. I want to put an end to my nightmare. I refuse to live in fear. I refuse to be obsessed with the thing in my leg. I want to get it over with myself. Terminate. I don't know how. I only have natural supplements on my table. I despair. In one moment I realize I may not be able to escape, but I choose to live without fear, under any circumstances. My dear thing, I am looking at you from above.

I don't know if you learn more by exploring the outside but I am confined to the inside. I re-make the world in my bed. I draw what I see, what I am more tempted to look at, my leg. The world is my leg. The world is sheer deformity. It grows more scary than I thought it could. Looking into this world, with which

I identify, I am appalled. I fear. And I keep looking, it's my world. I start to explore it. I am representing it, drawing my fear, my obsession, my world. I am drawing the bandages on the holes on the thing on my leg. For every point I make a cell dies. I become obsessive about points. The tumor replies with needles. It wants more, more attention. You cannot make me fear, not now, you are my world. The needles I feel are like rain, every drop brings a sensation. I like this rain, it's warm. This is a good day.

It's like a moon of a distant planet. It has craters and a surface between skin and stone, a stone on a windy shore changing shape in a circular manner. It spurts thoughts, it spits ideas, it exhausts me. It tells me to be wild. Find snow, undress, throw yourself, put the thing in snow, breath, enjoy, this is better than a hospital bed. There is no snow but I remember the shiny white surface where you can look and look, lose your mind to beauty. You have to do what it says, otherwise it grows bigger and soon you will be only its satellite. I want to gravitate around it, what if it is really alien, planet, biology, me, you, carbon compounds or non. Doctor, I would like you to perform a planectomy on my leg. I promise I am satellite. I will revolve. We will shape the space.

Spirula and Medicine

They tell me to go home and wait for my end. I fear going back home, jumping into the image they created for me. I am on the bed barely breathing. I deform it, the image, it's the struggle between realities, they want to impose theirs because otherwise their ground becomes cracked. It's easier to sacrifice a human than to shift a bit your paradigm. We know, human doctors think they know, they go to bed assured that I am a piece of meat. They made a script, imposed it on people like me, we have proof, we know better. Reality follows the script if it is believed and they spent centuries to impose it on us. My reality just performed a triangle choke on theirs. I am home, at Sana's, on the bed, red cheeks and all, playing with my cats. I am alive.

I have a secret. Whatever horrible thought comes to me, from the planet within, or who knows from where, I embrace it. Come little dark thought, expand, I want to know why you are here. I will manipulate you and you will manipulate me and in the end you will be no more. Many thoughts or states sublimated within me during these months.

When I am agitated during the night, I am pretending this uncontrollable state is my will. I perform my states, I get out of bed and I let the restlessness take over. I am punching the air, I am raging like a wild animal.

Realization: I have never trusted my body and its responses. We are taught so by education. Fever needs to be kept at bay, symptoms have to be read by specialists, you don't own your body, it is like a foreign coat you have to take care of and beware of it, look for signs, gather evidence. You are outside of your body, you analyse it scientifically but what does this mean. It means that you are placing it in the scripts written by strangers who are afraid of the wonder of reality and want to restrict its vastness to a few predictable scenarios.

The body is real but what we think about it is fiction. Medical views are the fiction imposed on us by

modernity and capitalism. This is a consensus fiction. How you regard the body, how you name, determines how you act upon it and also how it acts back. We are free, and the body actually calls for individual fictions, or for fictions that give it trust and freedom. Perspective creates reality. To change the standard perspective is almost impossible. It cannot be done mentally, it needs different practices - to practice ways to interact with the world that give back reality its multiplicity. We actually don't truly interact with the world anymore. That is because we know too well the practices that are possible, and so they will give back the same outcomes. The body is as alien as the world. And we have to embrace its strangeness. Especially when we need reality to be crazy, when we are ill with no chance at survival from the standard perspective. I don't want my reality normal. I need it off the hook.

Spirula and its Symptoms

What is a symptom?

Healing is a poem written with the language of symptoms.

Sometimes the symptoms require amplification, spatially, inside or outside the body, ignoring, fighting, acceptance by subjective study, transformation by imagination - metaphorization, deepening of their perception until they become something else, so abstract that they lose any conventional signification, and there are many other possible operations that one can perform upon symptoms. They can be danced, drawn, etc., or even just imagined in a physically passive way. There is also a rhythm of these operations upon the symptoms that is very individual for every person and even every period in a someone's life. Healing is both the operation and the rhythm of the change of these operations. The rhythm is energy, life, it is what cannot yet be understood, that is why there cannot be any previous schedule, meaning or explanation. The poem.

The body calls for a different language. You have to enter the unknown. It cries out loud through symptoms that it needs to become poetry not theory. This is a sign of intelligence of the soul.

Sensations - we feel them in one place but we can move them expand them shrink them keep them in movement project them outside the body make them circulate part of a bigger language. This elasticity of sensations, discomfort or pain sets the poetry in motion - it messes up with the consensus language of the body.

I hate that the doctors nullify my poem with their order words.

Healing is an alchemical process.

Moving, reinterpreting, resymbolizing.

The body is abstract. It occupies more space than where it finds itself. That is why it can transform its anatomy into jungle.

I grew a jungle on my body to handle my symptoms. I am delegating the care for my body to an

imaginary world.

I have a volcano in my leg, a raging wild animal rising from the void in my lung, a rainforest amplifying my short breath, a wolf in my consciousness, a wild pig scuffing out the root node in my chest, a sloth calming the restlessness of my heart, a jaguar spirit coming to get me, to make me a free spirit, and I am flying over reality, jungled up, towards life or maybe towards death.

Spirula and Experience

The first who claims to be actually able to simulate crossing of edges is the mind. Ideas tell you that you have done it or are about, if you just dare to circle a bit more in the loop of thinking. Just that the spiral never ends and one day you find yourself burned out in bed being called by the body to the reality of the ideas you perhaps liked to fancy. I mean the alien, the radically unknown, the limits of experience, the performance as life, life as art... The mind already replies aggressively that maybe you are in a loop with this as well but I reply that now my actions can take me from death back into life, that the edge is now fully lived.

If you are lucky to have escaped a disease conventionally you can go back to the radicality of thought as if nothing happened. Some may experience a new surge of life. Almost everyone wants to change, especially if the threat is big enough. When my existence has been put at risk thought felt deeply humiliated, it stopped. For days I have been just feeling that I exist and that is my protection, like a lucid breath inhaled and exhaled by heart.

The diagnosis triggered two opposite forces: great fear and great courage - one that would overcome the greatness of the fear. In the great fear is a constellation of white coat talk, alarmed best friends, and all Western conventionality regarding to how you treat something for which medicine has no promise. Already in doing the list a friend shouts in my head that I was jumping to conclusions that there was no promise. I shout back, shut up, because I've been through the vicious circle of guilt too many times. And I know it's not a real friend, it's not even the friend, it's me performing my own enemy as my well-meaning friend. I like enemies if they are like the Amazonian figures of enemies - the aliens whose perspectives I can eat to become what I could never alone become. In the great courage are my dreams, my energy, a deep inner feeling of abandoning myself to the unknown, my lover, my cats, my new friends and therapists in Vienna and Portland, Brazilian shamans, other crazy sick people, aunt Sana, the smell of the forest, the speed of skiing, all my enhanced experiences of nature, a butterfly on my hand for more than one hour, deers, jungle sounds, the feeling of the ocean, warmth in general, and I cannot but artificially close the enumeration.

Drawings, with eyes closed, notebook on the chest:

<https://photos.app.goo.gl/eQqnHHdDer94vB2k6>