The gift of disease (1997).

by Kathy Acker.

I am going to tell this story as I know it. Even now, it is strange to me. I have no idea why I am telling it. I have never been sentimental. Perhaps just to say that it happened. In April of last year, I was diagnosed of having breast cancer. I had had a history of breast lumps but, until this time, none of them had been malignant. A biopsy revealed that the mass involved was less than five centimetres in diameter. Unlike most medical stories, all the horror in this one occurs in its beginning. Gradually there will come an end to the fear.

Most of what happened occurred in the US. What goes on in Britain may be another story.

Since cancerous cells were found at the rim of the tissue that had been extracted, my surgeon told me that I had two choices: either a lumpectomy with radiation or a semi-radical mastectomy without radiation. Given the size of the mass and the findings of his examination, he said that, according to statistics, there was only a 30 per cent chance that the cancer had metastasised, or spread to surrounding tissue. If it hadn't, I wouldn't need chemotherapy.

I was terrified of cancer. I feared chemotherapy more.

At that time I was working as a visiting professor at an art college and so did not qualify for medical benefits. Since I didn't have medical insurance, I would have to pay for everything out of my pocket. Radiation on its own costs \$20,000; a single mastectomy costs approximately \$4,000. Of course, there would be extra expenses. I chose a double mastectomy, for I did not want to have only one breast. The price was \$7,000. I could afford to pay for that. Breast reconstruction, in which I had no interest, begins at \$20,000. Chemotherapy, likewise, begins at \$20,000.

In the Bay area of California, where I was living at that time, again according to statistics, one out of every seven women was being diagnosed with breast cancer. A friend of mine, a noted nutritionist, told me that experts are predicting unofficially that these figures will rise to one in three and that The Center For Disease Control in Atlanta, Georgia, has been called in to investigate. None of this had yet been let out to the media.

Even according to officially-approved statements, the rates for breast cancer in northern California are the highest in the world. Moreover, it is not known why so many women, the majority of whom are white career women, are developing breast disease.

Breast cancer, in the realm of western medicine, is big business. The two largest industries in the US are weapons and medicine –cancer research and care are a mainstay of the latter.

Having been diagnosed with cancer, I consulted both my acupuncturist, and my nutritionist. I had been working with both men for about six years. The latter put me on a high anti-oxidant diet. The former informed me that there was nothing he could do, that acupuncture does not deal with cancer.

The double mastectomy itself took place three weeks later, at the very end of April. It was at the same hospital where the biopsy had taken place, one of the finest in San Francisco. Even the waiting room into which I was ushered –after I had pre-paid all my costs- felt warm and safe. I spied conveniences: a phone and a television, a closet in which to hang my street clothes, a private bathroom. The nurses who visited me in order to administer the necessary preliminary tests and preparations were both kind and friendly.

One of these nurses told me that my operation had been moved back an hour. Ten minutes later, she wheeled me –in a wheel chair I didn't need, for I felt healthy to myself- through halls, into a lift, through more halls to the edge of a second lift door. The walls and decoration around me were lovely: wood and dark red colors.

Now a nurse who I hadn't seen before brought me through two huge doors adjacent to the lift into and unheated hall. Various green-capped and green-clothed figures moved by me. While I was here, one of

the green figures introduced a preanaesthetic into the drip that was plugged into my veins. As soon as she inserted the liquid, I felt cold creeping around the base of my skull. My brains were nauseous. I knew that I didn't want to be here. Then I knew that I couldn't escape because my mind had been changed.

While this was taken place, a green shower-cap-like thing similar to those worn by all the figures around me was put on my head. It fell over my eyes: I could no longer see. Scotch tape was wound around what jewellery couldn't be removed and around the skin adjacent to it. I was being reduced to something I couldn't recognize.

The next room was huge and colder than the hall. In its middle there was something that was partly a table and partly a bed. Machines that looked like Dr. Seuss animals were connected to it. I was told to climb up on to it and lie on my back.

I want to describe as exactly as possible what it is like to experience conventional cancer medicine. However, I am omitting the more horrific details.

Thick straps were placed around my arms and legs, then buckled tightly. I remember asking, "Why are you doing this?"

"Because we don't want you to harm yourself."

While I was trying to figure out how I could hurt myself if I was under sedation, red suction cups connected to steel cords were placed on my torso. One of the figures asked me when I had last eaten. Before midnight, as I had been instructed, I replied. They asked about drinking. I remembered I had had a sip of water when I had woken up. The person who was asking the questions and taking my replies down in a notebook told me that I was in danger because, having sipped water, I might vomit during the operation, due to the anaesthesia, ad choke on my vomit.

I was scared.

The first thing that I did when I came back to consciousness, I remember, was to try to stand up, because I wanted to get out of that hospital as soon as possible. I wasn't staying the night, and couldn't even if I wanted to, because only people with medical insurance were allowed to. But I couldn't stand up. Downstairs, my lover was waiting for me in a taxi. An orderly wheeled me to the vehicle while I fought against my nausea.

What next happened I remember as if it were in a play. My surgeon had told me, before the operation, that I could begin exercising the day after it. But two days later, my left arm still wouldn't move. On that day, I had an appointment to receive my pathology report at the surgeon's office. I drove my motorcycle there, with my lover on the back.

In the medical office:

My surgeon We took out the rest of the breast tissue, and there was no cancer in it.

Me That's not bad.

My surgeon But I have to tell you that we took out eight lymph nodes. Six of them showed signs of cancer. I want to explain this situation to you. All of us are going to die...

Me, interrupting him You said that there was a little chance that cancer had spread to the lymph...

My surgeon That was before this operation. Now things are different. I will explain so that you can understand. All of us are going to die. Some of us are going to die in 20 years; some in five...

Me, interrupting him Are you telling me I'm about to die?

My surgeon No. I'm not telling you you're about to die. I want you to understand this situation. There's a good chance you'll walk out of here and never have anything to do with cancer again.

Me What sort of chance?

My surgeon According to statistics, at your stage of cancer, there's a 60 per cent chance of non-recurrence. If you do chemotherapy, according to the most reliable statistics we've got, those chances go up to 70 per cent.

My lover Doing chemotherapy raises her chances only 10 per cent?

My surgeon, sadly We don't know any other way to deal with cancer at her stage, except chemotherapy.

Me Tell me about cancer and lymph nodes. If my cancer's so advanced, how come there wasn't any other cancer in the breast tissue? Aren't the lymph nodes the body's filter? Couldn't it be possible, since I've been on a super-high antioxidant diet ever since the lump was discovered, that the lymph nodes have been doing just what they're supposed to do? Couldn't they be registering cancer because they've been cleaning out the diseased cells?

My surgeon Unfortunately, studies –and I've read the best- all indicate that there's no connection between diet and cancer. The same is true with regard to environmental pollution. The truth is that we don't know what causes cancer.

I have recounted this conversation as accurately as I can, only in order to make one point. The point is a realisation. As I walked out of his office, I realized that if I remained in the hands of conventional medicine, I would soon be dead, rather than diseased, meat. For conventional medicine was reducing me, quickly, to a body that was only material, to a body without hope and so, without will, to a puppet who, separated by fear from her imagination and vision, would do whatever she was told.

I'll say this in another way. When I walked out of that surgeon's office, I thought that I might be about to die, to die without any idea of why. My death, and so my life, would be meaningless.

The reduction of all that one is to materiality is a necessary part of the practice of conventional western medicine. Actually, I was this one thought: I knew I wanted to live. To live was to stay alive and to not be reduced to materiality. There was no way I was going to go through chemotherapy. I never got in touch with that doctor again, except to pay his bill.

My search for a way to defeat cancer now became a search for life and death that were meaningful. Not for the life presented by conventional medicine, a life in which one's meaning or self was totally dependent upon the words and actions of another person, even of a doctor. I had already learned one thing, though I didn't at the time know it: that I live as I believe, that belief is equal to the body.

The hardest part of my cancer was the walking away from that surgeon and from conventional medicine. Belief in conventional medicine, in what our doctors tell us, is so deeply engrained in our society that to walk away from conventional medicine is to walk away from normal society. Many of my friends phoned me, crying and yelling at me for not undergoing chemotherapy.

My friend's confusion mirrored that of medical community. Today, there is a health crisis in the US and it is twofold. While epidemics such as cancer, Aids and immune diseases in general –whose causes, according to the practitioners of conventional medicine, are unknown –sweep through the populace, the industry is less able to care for those who are afflicted. This isn't only because there are no known conventional cures, but also because medical insurance, as it has been set up in the US, covers too few people.

There are just not enough doctors, nurses and medical facilities for all but the rich. Faced with the enormity of what is happening, many doctors, such as my surgeon, say, "We might as well do chemo because we don't know what to do."

Even though I walked away from that surgeon, I had no idea where to go. I turned to the man who had been my nutritionist for five years and asked him for the name of the best nutritionist in the city. The latter read my pathology report and said, "There's only one way you can beat your cancer."

"What's that?"

"You have to find out what caused it."

Also, he advised me to pray.

When I walked out of that office, I was mad. Nobody knew what caused cancer. The incident remained in my mind. I was looking for someone to whom I could turn, rather than looking in myself.

Impelled by the fear that my time was limited, I began to learn as much as I could about alternative or adjunctive cancer therapy. The doctor who was my acupuncturist at that time, when I pressed him, informed me that the most accepted alternative cancer treatment was the Gerson method. Until the advent of the macrobiotic diet, the Gerson had been in the US's best known nutritional therapy for cancer.

In November 1946, the American Medical Association openly attacked Dr Max B Gerson. They subsequently destroyed his professional reputation and denied him malpractice insurance. Gerson was forced to move to Mexico; today the Gerson Institute, directed by Charlotte Gerson, his daughter, operates partly in Bonita, California, and partly in Tijuana, Mexico.

Most researchers and practitioners of alternative cancer therapies who have become nationally prominent have, in one way or other, been harassed or directly threatened by the American Medical Association. Dr Stanislaw Burzynski, one of the most prominent cancer researchers in the US, began his investigations by studying differential patterns of peptides (the fragments of protein in the body consisting of aminoacids). After a congressional hearing at which his cancer recoveries were touted as "miracles", he found himself outside the medical establishment and so without possibilities of funding. In the US, serious criminals usually undergo two grand jury hearings. Dr Burzynski has undergone five such investigations into work that many in the field –including Ralph W Moss, author of The Cancer Industry- consider brilliant.

Cancer is business.

If it is difficult to gather information about alternative cancer therapies, it is more difficult –in fact impossible- to evaluate each therapy. To walk away from conventional cancer treatment is to find oneself in a no-man's land between legality and illegality. After two weeks of intense research, I was more desperate than when I had started.

The nutritionist's words, "You have to find out what caused it", were a thorn in my brains.

At this point I walked completely away from the society I had known. I took a leap of faith, turned to Frank Molinaro, a psychic with whom I had worked for about a year, and asked him for help. He referred me to Georgina Ritchie.

As I did this –as I sought out the help of Frank, then Georgina- I saw myself, a person faced with her own death, and the meaningless of that death, turning to psychics, and I laughed.

Though I had known Georgina Ritchie for a year before I consulted her about my cancer, I hadn't really known much about her.

In her own words, Georgina had acted "as my family, as my class had expected me to". Graduating in economics from Barnard College, then the sister school of Columbia University, she had married "a proper husband", a well-known Hollywood film director. "I had been told, as all good girls did, to share my husband's work. So I began to learn photography."

When a professor who worked at the Humanist Psychology Institute in San Francisco invited her along on and expedition to what used to be the Inca empire, and then elsewhere to meet psychic healers, the Smithsonian Institute assigned her to take pictures of all she was going to see.

"In Mexico City, I saw a kidney transplant done with a rusty knife," she told me. "The knife went through the spine, severing it. I saw the bad kidney taken out and the good one inserted. After the operation, since it was a psychic one, the patient just walked away. She hadn't felt a thing. As far as I know, she's still alive. You know, I have copies of all those pictures. I watched a healer who has clinics in São Paulo and elsewhere perform psychic brain surgery. He used herbal concoctions; I saw him close the wounds with his own hands. Then there was a healer in the Brazilian jungle who incorporated the multiples egos of schizophrenics."

"Had you always been interested in shamanism?" I asked her.

"Before I went on this trip, if anyone had told me I would become concerned with all this stuff, I would have been horrified. The only thing that prepared me for what I now do was a healthy distrust in western medicine. My dad was a doctor."

When they returned to San Francisco, the professor, whose name Georgina will not reveal, "because he's a creep", took her under his wing. He taught her how to lead patients, sometimes by means of trances, through regressions, childhood and past life. When he began to absent himself from sessions with patients, Georgina, in effect, temporarily took over his practice, and then began her own. At that time, she was suffering from allergy; her allergy doctor, who hadn't been able to help her, started sending her his patients when he saw that she had been able to cure herself.

Georgina said that she would work with me and she sent me to Greg.

My meeting with Greg Schelkun signalled my entry into a school. A school in which I, who had done things such as bodybuild for most of my adult life, began to learn about my body. I want to introduce two of the people I met in this school.

Greg is a big, gentle man who looks like a midwestern American farmer. Originally he wanted to be an artist. Graduating from Dartmouth College in art history, he intended to go to Japan to study art. When his mother, ill from a non-specific abdominal infection, she asked him to accompany her to the Philippines to meet a healer, he got his first taste of what was to be his work. The healer cured both the mother's infection and the son's migraines. "I couldn't deny what I was experiencing," he told me.

Stubborn and still wanting to study art, Schelkun travelled to Japan. There, a British artist, Rodney Cladwell, showed him that he should to work with Henry Moore, then visited him in 1972. "He was one of the most important people in my life," says Greg.

Moore told the ex-university student that he would be better off working on his own, but nonetheless, Moore would accept him as an apprentice. Since there was a waiting list, there would be a delay of a year to 18 months.

"I was still intrigued by healers, wanted to make a film on them, so I went back to the Philippines. Two days before I was supposed to leave, I met Placido. He was living 'on a mission' to the hills in three days. I asked if I could go with him. I didn't know why."

Schelkun thought that he was going into the mountains for five days. Instead, he was there for two years. Then, on the invitation of a patient, he went to northern California. Word of mouth about his skills soon brought him patients; he has now been practicing in northern California for 20 years and has been written about in various American magazines, including Time.

I asked Greg what exactly he does.

"By seeing, listening, asking questions, I sense energies, how they're blocked, I want to make energy to flow freely."

"How do you do that?"

"It's up to your body..." Greg hesitates. I know that he tells me only what he knows I can understand. He is always teaching.

By "it" I presume he means disease –disease which is equivalent to life, for bodies are always changing, going through what we call disease.

"It's about learning. We're alive, so we can learn. Bodies are part of the challenge to learn about compassion. We learn from diseases: they are gifts."

I ask Greg what health might be.

"Health is a corporeal existence. We say 'good' health and 'bad' health, but we're only making up what 'good' and 'bad' are. We put value judgments on the body, whereas we should listen to the body."

"You're teaching me the vocabulary of my body, aren't you?" I'm trying to understand what Greg has been doing to me –or is it with me?- all these months.

"That's the first step."

"What's the next step?"

"To focus attention. That's how you get rid of symptoms."

"Is there another step after that?"

"You have to want to be well. You have to learn what well is. That can take a lifetime or five lifetimes," he answers in his laconic way.

When I first started working with Greg and Georgina, I had been confused about why I had got cancer. Three weeks later, I saw the network of causation so clearly I wondered why I wasn't more disease-riddled. Georgina remind me that if health is based on forgiveness, then I had to forgive myself. Again, I enquire what health might be.

"The body remembers, especially traumas," Georgina thinks aloud, "and holds these memories as scars, as wounds. Disease is when the body isn't in harmony, when there are areas of blockage in the body. So in order to lead someone to healing for I work verbally rather than Greg does, I go to the past. When a person goes through regression, childhood or past lives, that person is able to situate the trauma in the whole picture and so stop obsessing about it. For instance, take the blame off mummy and daddy, begin to see mummy and daddy as people situated in larger situations. All healing has to do with forgiveness. A healthy person is one who can say, 'I no longer have scars from the past that will keep me from doing what I have to do today'."

"What is health?" I ask again.

"A body that's in harmony."

"What about the mind?"

"The mind exists throughout the body."

During this period in San Francisco when I worked with Greg, Georgina and Ellie Wood –a former student of Greg's and now a healer who taught me how, through visualization, to examine my major energy centres-. I fell in love with someone who's English. At the end of July, when my healers told me that I was on my way to health, I moved to London.

Here I began working with Ken Lloyd, a Chinese herbalist, Beverly Katz, a cranial therapist, and Stephen Russell, The Barefoot Doctor. Russell is certainly the most colourful of this group. Deciding after his first term at university that he would rather be out in the real world, Stephen started importing Italian fashion into London. When he met RD Laing, Stephen told him that he was going to be his student.

"I don't take private students," replied Laing.

"You're going to be my teacher," Stephen exclaimed.

Ronnie laughed and took him on. They met twice a week, once for therapy Laing-style and once for discussion.

Then it was 1979, and Russia invaded Afghanistan. Convinced, perhaps strangely, that a nuclear disaster was about to end the world, Russell left England, his studies with Laing and his business, in order to take his family to the US. There he intended to meet up with Thomas Benyaka, the Keeper of the Prophecy for the Hopi Indians, whom Frank Waters had mentioned in his The Book of the Hopi.

After journeying more than 11,000 miles, Russell found the man for whom he was searching. "I asked him if the world was going to end, and Thomas Benyaka said, 'No, our prayers have taken away that disaster.' Then he said, 'You have to go away and heal yourself before you can heal other people'. At that time, I had never thought about the word healer, much less about me being a healer. I just wanted a way out. This man told me who I was going to be and then he told me that I had to go away."

Stephen travelled to Taos, New Mexico, and went to work in earnest. He studied with Joe Sawasso, an American Indian healer, Han To, a Chinese herbalist from San Francisco, and Morgan Shannon, a well-known Reichian therapist.

Though trained in different disciplines, Schelkun, Ritchie and Russell speak about disease in the same manner. "Disease comes from blockages of energy," says Russell. "I heal someone either by getting rid of these blockages or finding bypasses so the energy can again move freely."

"How do you do this?" Though Stephen has worked on me, or with me, many times, I cannot articulate what he does.

"Every person has two selves: a local and a transcendental. The transcendental self is the one who watches. I help a person get there, for if he can see or find how to heal himself."

I remembered Greg talking about disease as a school. I remember him saying that he is teaching me how to heal myself.

"I want to say one other thing," says Stephen. "If you look from the point of view of the whole, the whole is synergy. The whole universe is always moving, healing itself. It all comes down to faith."

Does it? I have listened so closely to my healer's words that, perhaps, I have forgotten to ask myself how I perceive healing. How do I understand what has been happening to me or in me?

When I walked out of the surgeon's office and didn't know where to go, I asked myself what I could know. Did I have anything in myself, in my life, that could help me know and so deal with cancer? My answer was: it takes strength to know.

Where, then, is my strength? Answer: in my work, my writing.

What are the tools of my writing? Imagination and will.

Imagination allowed me to envisage something other than surgeon's doomtones; will actualised that which I imagined. I was able to make a leap of faith and knock on Georgina's, then on Greg's, and Ellie's doors. I am discussing healing. Greg said, "First, one must want to be well."

What was this "leap of faith"? When I asked Georgina for help in fighting cancer, she said with certainty, "You will create your own healing." I took it for granted, as I think many of us do, that doctors are people who know how to get rid of disease, that one turns to a doctor in order to be cured of physical affliction. Though I no longer trusted conventional doctors, I trusted myself less. How could I heal myself of a disease as serious as cancer? I thought Georgina was mad.

My leap of faith was to believe that I could be healed and that I could heal myself. That I could heal without having to trust someone else with my life, as I had done with the surgeon; that I could be responsible for myself. Georgina proved to be right. I am the one who must heal in order to be healed. In order to heal, I had to question and even abandon certain basic medical paradigms. A doctor, for me now, is not someone who cures for, as Greg says, no one cures life. Rather a doctor is a facilitator and teacher and the doctor-patient relationship a spiritual, as well as medical, one.

The most radical paradigm shift, however, concerns the body. Since the healing work that I did, am doing, and that was done to me was mental and spiritual, as well as physical, I experienced my body either as having several aspects or as several connected bodies, as soul, as energetic or emotional, and as physical. I saw that the organs, the tissues and the cells physically remember all that happened to and within the body. I experienced the body as an entity separate from all other entities only in its physical aspect.

A final shift of paradigm concerns the experience of "going to the doctor" or of healing. Once —having left the surgeon's office and the realm of conventional medicine- I had grappled with, the passed through, the worst of fear, fears founded in birth and in childhood as well as in considerations of death, I felt only intellectual excitement and joy.

When I met Greg and entered the school of the body, I entered the school of the self. I thought I was, unwillingly, confronting cancer, instead, I was confronting myself. I no longer have cancer. To heal in oneself is to begin to heal the self which is always whole. I have written down some of what happened to me in the past nine months, though I as yet understand little.

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