

Appendix 2

Seth's story: Some indistinct ideas and reminiscences on cancer

[the moment
of diagnosis]

[1] "Oh well, there will be a surgery for sure." I heard doctor's surprised sentence behind me. I was lying, a cheek pressed against the polyclinic pillow, endoscope tube in my bottom. The physician looked into it as though it were a telescope, a [way into] inner space. An amazed, almost a frightened tone in the doctor's voice, gave me a feeling of relief. My long personal nightmare was over. There was something that a specialist could detect. A desperation, spleen, dreams, the feeling of helplessness were not only the results of my bad nature or imagination. "There is a growth, I cannot tell yet what kind, but it bleeds" the doctor continued. I knew it was malignant. I had felt it long enough. It was a relief, a month-long problem with haemorrhoids was over. Plain haemorrhoids would not manage to ruin the whole *soma*. Half a year confusion, collapse, the feeling of apocalypse, desperate depression had a confirmation: Growth! I came down from the examination table almost happily and pulled up my pants. Feeling relieved I made a date for the next polyclinic visit. They would call me if there were something to announce before that.

[individual
feelings and
natural
surroundings]

[2] Light snow was falling on asphalt; the sky was bluish grey as I walked out of the doors of the chirurgic hospital. Now life at least belonged to me. I was at least someone. Something had happened to me that did not happen to everybody at this age. I felt myself too young and at the same

time ready for the grave, both at 29 years old. What could have been the reason that life, which despite the years I felt was barely beginning, could stop already? What, yes what? I did not understand. Tram number ten turned into the stop. The vehicle and the few people sitting in it, the almost silent streets of Helsinki, the chilly frosty weather. Everything felt too ordinary, but at the same time festive. It was the feeling of a young man carrying death inside him. I felt like having coffee and buns.

[pre-
symptomatic
health
concerns]

[3] A half a year before that, work things began to make me nervous, and I reacted all the time with my stomach. I had to survive every day. The work felt more and more insane. I knew that it had something to do with being tired and depressed, but usually I was so involved with my feelings that the lack of sense and completing the tasks filled the days.

[the smell
of illness]

[4] One night before going to bed, my wife told me to take a shower, you stink. I had been sweating, I smelled it myself, the sweat smelled like insects. This is some kind of fear. I knew the smell of sweat changes through life. I took a shower. I remember the smell of falling ill and the darkness of that night.

[pre-
symptomatic
health
concerns]

[5] I fought until spring. Stressed, pissed off, easily irritated waiting for the summer vacation. Everything felt wrong, overwhelmed by the weakness of existence. I could not change anything, not make it better at least; dissatisfaction; looking for whom to blame was a daily thing.

[6] I waited for the time I could go to my summer house, the vacation. There, I get better. Every summer I had recovered from the lack of energy wasted during the winter. I took some additional unpaid vacation, which was fine for my employer. There was a long summer waiting ahead, and the pleasure of sauna on the lake shore. Mowing, berry-picking, piece and nature, birds singing and lots of small tasks to solve as one likes and can. I knew that by Autumn everything would be different, my mood would be better. Birds were singing, mild summer wind blew in the trees, I sat in the outside toilet, door open, enjoying nature and the summer. I had noticed that I had to visit this place way too often. It felt like I had to run there all the time. "Is it the vacation, holiday food, winter stress." At the end of the summer I sat there really astonished. The insects did not calm down. "It takes so long. My stomach has become only worse. In the city I shall visit the doctor, now it's the rotting month and maybe that's it.

Always everything that comes also passes. Fresh air will do some good anyway. The main thing is I am not afraid of autumn", I thought.

[7] The autumn in the city was warm. The summer seemed to be continuing. The tiredness did not disappear. I continued to visit the toilet all the time. Finally I had to go to the healthcare centre to complain, haemorrhoids. I related the symptoms and the physician prescribed baths. I felt as though I had a small fever all the time, or from time to time.

[8] I cannot remember how I managed with my work. There were new people working. I was like a strange and old employee who does not manage with his tasks. I was bad. I, who in my opinion had been doing a lot to be good and manage well with work challenges. Now I lacked the energy, I was absent minded, bad natured even. I did not manage at all. For a young person it does not look right or is hard to imagine this as a result of illness. Evil, really evil.

[pain story]

[9] Then the pain began. It got worse day after day. Somewhere between rectum and leg. A twinge that continued for weeks. The doctor visits. Haemorrhoids only. (The growth was pressing against the nerves). One beautiful autumn morning has stayed in my mind, I walked out into the street, the sun was shining, trees in the park were yellow. Life and my condition were fine. There was no visible reason for being happy. In the tram I noticed that the twinge was gone. I remembered that when it came back. I was down and broken.

[suffering alone]

[10] Work was unsuccessful, my wife was nervous about my condition. Did she think that this must be some kind of neurosis or something. My wife came home from work one day. I had already come in a couple of hours earlier, I sat and suffered from pains. I did not know what to do. The doctor's appointment was at the end of week. The full desperation and physical agony had controlled my mind. I sat and looked at her. I noticed how she got scared as she saw my look. I knew what look it was. A look frozen by agony begging for mercy. It was the same that my father had had few weeks before dying from cancer. The pain was harsh, but still you do not want to accept death as a matter of fact, although you know it is approaching. I had to hide my agony and act as though there was nothing big going on. I would go to the doctor on Friday and complain as carefully about my problems as I can.

[dream
experience and
interpretation]

[11] *Help, an explosion, I got hit, shrapnel. It had torn my stomach, the arm hurt, it was dark. Where was everyone. I remembered that I slept in a dugout and a bomb shell had torn apart my stomach. I was wrapped in sheets. Was I in the troop first-aid station already.* The night light was beside my bed. War. Morning broke in the hospital. Other patients in the room were still a sleep. I remembered being in the hospital. Yesterday I had the surgery. It felt empty where my stomach was. The painkillers cleared my thoughts, the body that is my own life was dependent on a dripping bottle. I recalled yesterday. In the clinic ward there were at least 20 patients, some of whom had had their surgery yesterday. The ones who had been there already for a week looked at us with pity and understanding. They knew what it was and what was coming. This day was everything for me. I had already slept for a couple of hours. Where did this image of war come from. The day before I had read in the *Seura* newspaper about a new play called *Unknown Soldier* in the city theatre, the characters and rehearsals. This was my private war. You have it despite the era, the blight of every generation. Everybody must define his or her own position in life's battle on a personal level.

[self-
negotiation
in hospital]

[12] I laid there and thought, what would I give for not having that day; a lot and nothing. This moment was everything I had. If I will not survive it, I will not survive at all. The next surgery patients were brought in. Carrying surgery clothes. I was forced to give my body into the hands of others. Being on a narrow surgery table having on only surgery gown was a surrender, donating your body to the hands of professionals. They did their work, I gave my whole life. At this point I had no demands. I trusted.

[individual
feelings and
natural
surroundings]

[13] Feeling fine I looked at the wooden columns in the chirurgical clinic. The nice wooden carvings curved masterfully. What a weight those columns could carry. The whole weight of the building with great harmony. How humans master it. Being intoxicated I was enjoying the beauty of human craft. "That there can be something so genial and beautiful." I stared at this wonder for hours. The nurse came to ask how I was doing. I was on the top of my life. Not ill or anything. Fixed at once, I could go anywhere I wanted. So well things had turned out. I smiled happily. I was healed from all my troubles in one day. I fell a sleep.

[14] My friends were beside my bed when I woke up. Everything was fine. I must become well now.

- [self-help] [15] On the next day I had to walk some steps. It felt like a line of knives in my stomach. The wound is healing I tried to think. It was the time for physical pain. This was pure pain. Knives in the stomach. I did not want to take the painkilling shot. I tried to keep it for later, hoping it would help to cure me as long as I managed to survive the ache, before the shot was given and closed me in cotton.
- [religious experience] [16] It was dark, it had been raining outside, now there was fog. The patients' hall was quiet. Carefully I pulled myself up with the IV stand to look out of the window. A November evening in Helsinki. On the wall of the opposite house was a white being. I looked more carefully. This was a Christ. A monument that was there wishing everlasting and continuing blessing to human kind. I had never before thought about religion in such a tangible and personal way. How much suffering everyone in here had to soothe by themselves. Yes, in you and in me; in everyone of us both in friends and enemies. We were all here. There had to be some power and it had to be coming from somewhere. The old sources were finished from my side. The fog made the white monument' surroundings glow with some light. This was like a vision.
- [life in hospital] [17] Before going to the hospital I had been thinking of reading and writing my diary, but no chance for it. Being ill was daily work. Food, cleaning, toilet, medicine, shift changes, day, night, visits. That is it, at most waiting to go home.
- [Patient-doctor communication] [18] Doctors visit. The group around my bed, everyone looking at me. The caring doctor stays to explain my situation. They had removed some suspicious glands at the same time, the results come in the end of the week. "So there was something to wait for. The information comes on Thursday."
 [19] On Friday I asked for the results, as no one told me anything on Thursday. The doctor promised to come later to give me the results. There was something to tell. I knew. I was ready. To take even death from life. We went into the procedure room. There was only one chair, the doctor asked me to sit on the edge of the bed. He sat on the chair, lower than I. He was few years older than I. It was a difficult thing to tell. "Having such profession you get harsh, you see so much, everyone has something", he began. I saw that he was comparing himself with me. I felt sorry for him, I appreciated his work. I knew he got fine compensation for it, but I myself would not have been able to do the doctor's work whatever the money was. "We found something in those glands", he managed to say. "What should I do and will there be some

additional treatments, I asked for continuation treatments.” I knew I did not want to have any more treatments. This surgery was in my opinion enough, I could not take more. “Tumours of this kind are not curable with X-ray treatments, so we just follow how it is developing.” “Does the food have some significance?” I asked. “You can eat bran, it has some significance”, the doctor advised. I thanked him and was relieved. No more procedures.

[evaluation:
post-recovery
time]

[20] The clouds were travelling from west to east. I looked at the fair weather clouds, their golden edges lit by sun against the blue sky. The clouds took new shapes, new faces until the whole shape was new. I had looked at it for a long time, without the feeling of losing time. I remembered doing the same thing as a child. I was in a similar state of mind. K. asked me for coffee. The clouds at the summer house. Half a year had passed after the surgery. K. said that, “you have learned to hang around, before you could not do it at all. You had to do something all the time, fix something, make something.” I had made a decision to survive this summer. “Next summer, even, even if it is the last”, was my thought back then in the autumn, after the surgery. Now it was here and I looked at the fly on the window. The grass was green.

[21] Last winter after the illness leave I did not feel like working. My memory was bad. The result of anaesthesia and medication I suppose. Acquaintances and work colleagues were shocked hearing about my case. Certainly they had almost buried me and created a tragic story on the top of it. But I lived and after the illness leave I returned to work and blamed others for oversights that had taken place while I was away. I think that before I had been too kind, I made promises and I could not say no. As I did so, I did it too harshly. Now I decided that this comes to an end. I did not give a shit. I didn’t have much to lose. I had decided to have the next summer to myself, free and in my summer cottage.

[the meaning
of cancer]

[22] I could not stand a busy life. I reacted as if I was allergic to it. I lost the point, the attachment that made me function frantically. I had lost the habit to live in a hurry, I was recovering. I could not escape into a busy life, I still cannot do it. I felt that being busy was a sin, a way to pass the moments. I noticed that people who were not constantly in a hurry managed just as well.

[evaluation:

[23] During the winter my mind was busy with questions,

post-recovery
time]

how life can be so short, thirty years of human life is nothing. I was just at the beginning. At first the elementary school and the gymnasium. Now they tried to push in my hands the graduation papers of life, although I felt I had not even entered it yet. Now I should have the courage to make things true, as I had dreamt when I was young. Make dreams true. I started to work partly because I decided to work and learn. A donkey following the carrot. I had courage, now or never was tapping at my work table with its fingertips, through my window were some garbage bins and the wall of a factory. Here sat a man with his destiny. Waiting for ever was no longer possible; but first, the summer. I'll do it if I am still alive, after a year or something like that. Was there some decisiveness, a contract with life, I'll do that first and then things will happen or not. I began to gather courage with the back ends of my mind. With losing your life you'll gain it. Could a win be a loss? I felt that the ceiling of my office hung like bellows strings, like a lunar landscape. I observed it long moments and let my thoughts flow.

[self-help]

[24] "Bran!" I recalled doctor saying: "It might help." Short life, so short that it is not explainable. In such a short time I was not ready for heaven, despite whatever sins would have been forgiven. I did not know how that I had come here or why I was as I was? What character had my nature, thoughts? Was I just a product of environment, who was I? Nothing can be explained plainly by birth and death. People came from somewhere and somewhere they go. This story is longer, not just a beginning and end. I ate bran.

[conclusion:
the meaning
of cancer]

[25] The cancer was discovered approximately fifteen years ago. Since then many things have happened in my life. An unsuccessful business, divorce, studies, a change of profession, loneliness, travelling, life abroad, unemployment, some brief moments of happiness: everything that belongs to this life. I do not feel that I am living under some kind of protection, that I can safely recall and analyse the truths of life. The other way around, in fact. I can note that falling ill is still the most precious experience that I have had in my life. I experienced something when I was young. I got some perspective and the kind of depth that usually comes later. Clearly I can note that cancer is the best and worst thing that has happened in my life so far. My most precious experience.

Hanna's story: What did I think before I fell ill with cancer?

FOR INFORMATION

I send my writing so late as I have been really busy at work – I hope it helps when you select materials for your book. I remind you that I wish to use a writer's name if you publish the text. Is my writer's name too long?

[The time before the diagnosis] [1] Precisely seven years ago I had my 30th birthday. The day was really rainy, in the kitchen two mothers of my age waited for party coffee and on the floor three six-month-old babies tried to make each other's acquaintance – my own daughter was annoyed and tired like me. I had just made an appointment at my gynaecologists and I was still wondering if it was reasonable to visit a doctor based on such unsure symptoms. I wished that the neighbours would drink their coffee fast or the babies would make such a fuss that I would get rid of my guests and think about my situation in peace.

[Pre-symptomatic health concerns] [2] Already a couple of months after birth giving I had felt a bump in the lower part of my belly. After the birth a gynaecological check-up revealed that my uterus was not shrinking well and I was given some medicine. This information was enough for me during the summer. Later in the summer my sister asked if I was expecting another child. I was a bit upset and told her that I was, and that my weight had dropped compared to the time before pregnancy. A bit later I noticed that I could not lay on my stomach when I played with my child – I had to keep my backside a little higher and turn myself to the right because something was pressing in the stomach. My husband also felt that the stomach was a bit weird when he pressed it with his hands. This was the knowledge that made me call for a doctor's appointment. I also said that I was feeling dead tired - by accident I chose the right expression to describe my feelings. Whenever possible I slept. I fell into sleep that felt endless and impossible to wake up from. I argued with the doctor that it was connected with childcare, although my daughter was well behaved and let me sleep and my husband helped with everything.

[The moment of diagnosis] [3] A week later I visited a private doctor. As the internal check-up began, the doctor literally turned white: "The right

side is fine...but...on the left there is an ovarian growth! It grows here under the uterus.” I understood the reaction of my long-term gynaecologist – her daily job was at the cancer clinic. The ultrasound examination that was done the following day did not give any clarification of the nature of the growth; the general conclusion was that the growth was big, but no way was it cancer. I was referred for surgery at the cancer clinic. More studies at the clinic did not bring any new knowledge, and the structure of growth stayed unknown. The doctors found out the truth in the surgery room, and me a day later when I was awake enough after a long anaesthesia and painkilling shots.

[Patient-doctor communication, the moment of diagnosis]

[4] The female surgeon kept her hand on my knee and looked aside slightly saying briefly that the growth was bigger than expected, that it was a cancerous growth and the uterus and ovaries had to be removed, as malignant cell mutation had also taken place on the right side. The surgeon said that everything was removed and the growth had not been attached to anything, although it was 15x20 centimetres – almost as big the head of a new-born baby! The doctor realised she should shut up, so I had time to understand. “Now it is in me”, was my first thought.

[The meaning of the illness]

[5] I was not then, and I have not been since, bitter because of my illness. I have never asked myself why, exactly, I was the one to fall ill. If I thought that way, I would have wishes someone else was ill instead of me. I was satisfied when I found such a human side in me.

[Talking about cancer to her husband]

[6] I asked the doctor to call my husband so I could explain the situation to him myself. The situation was dream-like; our happy baby waking in her carry-cot, my husband on his knees crying beside my bed trying not to push the tubes that crossed the bed, I was swollen and carried away because of the medication. I assured him that the surgery was successful. However, at the same time, I had to admit that I was about to start with cytostatic cures and so we should not make any long-term plans. My husband told me later that after coming home, he had been cleaning for two days, crying when the sound of the vacuum cleaner was loud enough.

[The treatment]

[7] The phase of uncertainty known to all cancer patients, which never ends fully, began in our lives. I felt extremely sick. After childbirth the ovarian cancer had developed at extreme speed and took away my energy. I had had no rest since giving birth, breastfeeding had demanded its part and now fear of the future strangled both of us.

[Talking about
cancer to others]

[8] I talked about my illness only to my siblings and some close friends. I forbade them to talk about it, but the harm had already been done. My sister in law did not listen to my request and she talked about me to a female relative even while I lay in hospital! That was a big shock and offence for me. At the hospital this was my greatest sorrow. I was angry because this thing that I could not understand myself was part of daily discussion already. I closed my relatives' mouths with one brief and angry phone call to my sister in law. Since then she has never asked how I feel.

[The
significance of
social support]

[9] My being ill happened at the time when the state generously supported families with children. When I went to hospital I always got a babysitter – something that really helped me. The biggest help for our small family came from the god-mother of our child, a friend from my study days. She left her work to take care of me and the child during that time! She lived with us, we took care of housework and I could rest and take walks as I felt. For me the situation was ideal, because my husband had to travel a lot for work and make rather long days. Year after year I become more and more convinced that the help from close friends in these first months saved our family from many sorrows later. We both had time to suffer and pull together our strength without being worried about taking care of the baby or cooking. Organising daily life sometimes takes more effort than fighting illness. Our friend was also an exceptionally happy and compassionate person so being with her brought some colour and new ideas to an otherwise closed home. We did not need others.

[Self-help]

[10] I carefully followed the doctor's orders regarding walking outside. I pushed the pram along smoggy and rainy paths and tried to understand what exactly the doctors meant by not making any long-term plans. They suggested concentrating on gathering strength for the next treatment. Naturally it was good that the doctors did not promise I would be cured at the beginning, as they were equally unaware of the outcome.

[Thoughts
about dying
and death]

[11] During the autumn I organised the funeral in my mind. Particularly when walking, I prepared various *in memoriam* speeches and farewell occasions. I thought how shocked my colleagues would be as they received the news of my death. I cried at my own thoughts, but luckily the days were grey, so passers-by did not pay attention to my red nose. There were opportunities to tell people about my illness, but at my

workplace there was no one suitable. I did not want then, and I do not want now, my workmates to check my wellbeing and ask, in awkward situations I suppose, about the course of my illness. The self-pity walks worked. After those I was for some time fed up with the subject, hungry and tired, so in this way a couple of hours passed again as they were supposed to.

[Biomedical
treatments
and self-help]

[12] I was treated with chemotherapy once every four weeks, the procedure lasted half a year and then I had follow-up surgery. After eight weeks of sickness leave I weighted 49 kilos, I had lost six kilos. I looked like a pile of dried bones – sometimes I felt like a convict in a concentration camp. There is no need to describe feeling sick and examinations – everyone who has been in hospital is aware of them and there is no point scaring new patients. Whatever the illness might be, becoming well is largely based on one's own will. I made it clear in my mind – the doctors take care of their part and I mine. For example, if I had not been forcing myself to eat healthily between the therapies, the bad blood counts would not have allowed new cytostatics and the treatments would have been cancelled. Logic, but so hard! I still did not want to be totally helpless, because I saw many people in far worse conditions and even they did not give up. Of course, I did not believe that one can stop cancer spreading purely by will power, but at least I could control my recovery.

[13] As I already wrote, the attention I needed, I received from my family circle. This solution was fine for me, and I supposed that this was the reason that I was not asked if I needed practical help. More than help at that moment, I missed conversations about marriage and my sex life: pregnancy, giving birth and falling ill, we had had no sex for more than a year. In my thirties I had no periods, only a vagina, and I took oestrogen every day to keep away the menopausal symptoms. After the treatments and sickness leave were over, I realised that no one had given me any kind of informative leaflet to read about such radical surgery and its influence on the life of such a (young) woman. Supposedly there was no such thing. As I had no insuperable difficulties, I did not care to return to the question during the follow-up visits to the hospital. These brief visits, to often-changing doctors at cancer clinics, do not really give an opportunity for such conversations.

- [Patient-doctor communication, the need for psychological support] [14] No one ever asked how big a loss it was to not be capable of having a second child. I had had a miscarriage earlier and now we faced a different sorrow, we craved our lost opportunities. In my opinion nurses, and particularly my personal nurse at the N. Clinic, should have brought it up as I did not know about this myself. Even a short conversation would have helped to clear my mind and give some basis for the discussions at home.
- [Returning to work] [15] After intensive care that lasted less than a year, I recovered. I went back to work, where no one could remind me of it, because they thought I had had been on maternity leave. Since I fell ill I think about my condition ALL THE TIME – the only moments I forget about it are when I take care of my child. I wonder, will I ever be able to push my illness aside. Being at work began to fill my thoughts so I had other things to think about as well.
- [The significance of cancer] [16] Until now there has been not a single day without having cancer in my mind (and hardly will there be one). I am sure it does not affect my actions. I am not spiritually down, I do not have nightmares and I am not afraid of falling ill again. However I know that I prepare myself for the moment when the illness returns. I could adapt the old advertisement for Flora: What did I think before I fell ill with cancer?
- [Concerns about her child's future] [17] I have began to prepare my daughter for this kind of illness. This has happened without noticing it. I told her carefully about my friends who have cancer and about one who passed away because of it. At the same time I have explained that one's own lifestyle means a lot, but at hospital they help everybody. Our little daughter misses a sibling a lot, but she has been satisfied with explanation that mother's stomach is so ill that new baby cannot grow there. I tell her everything, as her comprehension is sufficient and fear will not take over.
- [The importance of taking care of oneself] [18] The life has settled, my marriage is fun and my physical condition seems to be improving. In following the condition and my feelings I have perhaps gone too far, I will not observe my condition alone for a long time. But who would send me to examinations if I would not go to the doctors of my own accord?
- [Concern about the future] [19] During the summer I have had some stomach pains and three brief episodes of fever – the results come tomorrow. At this point the familiar fear is in my mind... hopefully tomorrow at that time this will be over.

Ruth's story: Melanoma and I

[The meaning of cancer, cancer aetiology] [1] When I hear the word melanoma it feels like a death sentence has been declared, but when it is going to be acted upon is not clear. This is what I have thought. I do not know how others experience it. Perhaps my own fear comes from the times of my studies. When I studied to become a nurse we had a lecture on melanoma. Regarding its different forms and classifications and how bad the chances are for people with it. So it happened that my own fear came true. Could it be that what you are afraid of most, you will face in your life? Could one talk about Karma – these are thoughts affecting one's destiny.

[Individual lifestory] [2] It was the first working day after the Midsummer festivities 1993. The phone was ringing, I went merrily to pick up, I was really in a good mood. I had had a wonderful summer holiday and I was in love, and there was still some vacation left. Everything felt so unbelievably good – although before the summer vacation I had had a miscarriage – that I did not want anything to happen to change this. I had tried to have a child for ten years and now; when I had become pregnant it felt it was a small miracle. But I had lost that miracle and that hurt. I have one grown up son, a son who follows his own path. Therefore, a small sweet-smelling bundle would have been a present from heaven. In my uterus a large benign growth remained that had caused the miscarriage. There were no options other than the removal of the uterus. I was waiting for notification from hospital regarding the procedure. So, I went to answer the phone. I picked it up and at the other end was the physician from our workplace. I realised in a moment what it was about. I felt dizzy. I realised on the spot that the almost insignificant birthmark had turned out to be malign melanoma. I was home alone. I fell on the floor, I heard as she continued: I will write to the central hospital, in two weeks they will send you an invitation. They must replace some skin on your legs, because normally they must remove lots of tissue and perhaps there will be some chemotherapy given as part of the continuation treatments. I listened to doctor's speech without saying a word and noted: I am totally puzzled; this was the only thing I was able to say throughout the phone conversation. The doctor understood fully – at least I assumed – how I felt. I put down the phone. My life was filled with emptiness. I felt as though I was dying on the spot, or actually I was thinking

that I cannot die, because I am fully healthy, happy and so energetic. I denied the whole thing. In reality I began to moan at myself immediately. I sensed a terrible feeling of chaos, so I could not even cry. In a moment I planned my own funeral so my son would have nothing to organise and no extra costs. He had been unemployed for a long time and because of this his life had slipped from its track. Drinking had taken over. But now, when he hears that I have cancer, will he become a total alcoholic, or will he stop drinking? They say that by falling ill people control their surroundings.

[The moment of diagnosis]

So, I think – how am I going to tell my son this. He has already lost all his dear ones, most recently his own father in spring a few years ago. My son who had a dark childhood that lasted most of his life. People bullied him at school – kicked to bruises, money blackmailed, experienced a marriage crisis, whatever. Now this. Oh dear creator, I prayed to God for power. And how should I tell my boyfriend? His brother died of melanoma. In spring, when I met my current boyfriend, the first thing he told me was about his brother. The brother had lived only half a year after he was diagnosed with melanoma. This had been a hard time for my male friend, because his brother was only 35 years old, married with small children, an apartment loan, etc. How this life had collapsed because of melanoma. Now this case was more than four years in the past, but it still hurts him so badly. Then I thought, how will I tell him that I also have melanoma? And what about my sister? How should I tell them? We have already lost one sister to cancer, but this was a long time ago. My sister was ten when she died. I was eight years old then.

An hour had passed since I heard I have a melanoma, and in my mind I have gone through terrible things. I panicked and had the feeling I could not breathe. The greatest anxiety I had is because of those close to me. For me it will be easy if I die, but those who stay here – I began to cry – I do not know, did I cry for them or for myself. My two cats looked at me, eyes all round as I sat on floor and cried.

[Cancer aetiology]

[3] I looked towards the window and saw the sun shining, the summer was at its best. I hated the sun, although I had loved it so much before: now I sensed it as my enemy. Although with my inner confusion I realised that melanoma cannot be caused only by the sun. The illness predisposition could be genetic – what about viruses? I easily got herpes on

my mouth and erysipelas on my legs. Whatever caused it, the truth is that I have melanoma.

[Talking about cancer to others] [4] I waited for the call for surgery. I was filled with terrible fear. The call came rather soon. At that time, when I was waiting for access to the hospital, those two weeks were the most terrible period in my life. I could tell neither my son nor my boyfriend – no one – what was wrong with me? I turned really aggressive. I thought: as I shall die I shall act really badly, then no one will miss me when I pass away. They wondered at my behaviour. Until, on the 11th of July, I said that the birthmark on my feet was malignant and tomorrow I must go to hospital. I could not say it was melanoma. I could have told my son about melanoma – but I was afraid of my boyfriend's reaction.

[Suffering alone] [5] I left the thing hanging in the air. It was the end of July and I went to the central hospital, the department of chirurgical procedures. I was accepted really well. The main physician came to have an interview with me. He asked if there had been any cancer in my family, had I been a great sunbather, is the (red) colour of my hair natural etc.... I had to give all positive answers. They showed me my bed, I sat on it. It was like a ship going down. I stayed there waiting for the doctors participating in the procedure. The anaesthetist was a middle-aged woman, very friendly. She took a chair and sat down by my bed and told me about spinal anaesthesia. Then a typical surgeon came. He stood by my bed his hairy hands placed on his hips. He was about forty, dark, a bit short but quite interesting looking. He said professionally how the surgery is done. That is, the surgeon will remove tissue from large deep area and take some skin for grafting from the thighs. He was sorry that there will be a deep hole in my leg. Well that was the last thing I cared about at that moment.

[Talking to her son and husband] [6] After the doctor's visit I had some free time. I was suddenly terribly home sick: I had to get home. So we agreed at the department that I could go home for a night and come again in the morning. The nurses gave me instruction on how I should prepare myself in the evening, and the sleeping pills that I can take if I felt the need. I was at home as though for the last time. In my mind I said goodbye to my son, boyfriend and cats. I called my sister and told her what was happening, and although I was playing everything down, inside I was crying. I had already given up and accepted my destiny. It seemed that people around me accepted it as well; my son

and my boyfriend acted as though they did not want to talk about it. Then they said that no wonder you have been so weird, depressed and tight lately. I admitted that I did not know how to tell them about it. I realised how hidden sorrow can harm one's surroundings. I slept well overnight, partly thanks to the sleeping pills, partly because the night before I had been awake, and partly because I had begun to accept the situation.

[In the hospital,
patient-doctor
communication]

[7] Early in the morning I went back to the department. I felt as though I was having varicose vein surgery. I got an open shirt, went to take a shower, got some pre-medication and after that I was not allowed to rise from my bed – I was waiting for my turn. There was no need to wait long, a young nurse came to my bed. She held a paper in her hand, which she looked at saying now we can go. The way to the surgery hall felt long. I was moved to the surgery table. I got the anaesthesia into my spinal cord, a moment later my feet felt heavy as lead, as though they were frozen. My leg, where the birthmark melanoma was found, was placed on a surgery stand. I felt mystical; I saw my own leg (although it was covered with a green sheet) but I did not feel anything. In the surgery hall the radio was on; I concentrated on listening to it and at the same time exchanged a few words with the anaesthetist.

[Surgery]

[8] The surgery lasted 45 minutes, then I was taken back to the ward. I noticed that the surgeon had made no skin graft – I really did not understand how the surgery had been done. As the operated leg was well covered by bandages, I had to wait until they came to tell me about the surgery. After spinal cord anaesthesia one cannot rise one's head because it might cause a heavy headache. There I was on my back and stared at the ceiling. The nurse came to measure my blood pressure. She could not tell why the surgeon had not made any skin transplantation. I was suddenly overwhelmed by fear, helplessness, I thought that the melanoma had already spread so widely that there was nothing that could be done.

[The significance
of cancer and
personal
lifestory]

[9] I was thinking of my life in the past – what have I actually completed? Was there anything still to do – I felt such guilt. Particularly because of the mistakes I had made with my son. What if I die how will he survive?

[Being a
patient]

[10] Mealtime came and a helping hand brought the tablet to my table, and even wished me *bon appétit!* I had some thinking to do – how to eat – I had to lay on my back and

could not raise my head. I thought about calling the nurse, who could help me, but I gave up as I saw they had other things to do. I placed the dish on my chest – it was soup – luckily I found a spoon, otherwise eating would not have been successful. Despite this half of the food was on my chest – I was not even hungry. However, with soup on my chest my expectations of quality of life changed entirely. Now I understood what the most important thing in life is – it is not money, fortune, your position in society – it's love and health.

[11] I thought about the patient's situation and how humble you feel. I had no self-esteem; I was fully at the mercy of others. It is humiliating to pee in a bedpan, it took hours until I managed it. Although the personnel were friendly, I was still troubled. They could not imagine that I was as helpless and unaware, as all the patients in the room were. That fact that I was a nurse was meaningless. I had a need for additional information, advice, support, for someone to hold my hand at least. They presupposed that I was strong, although I felt that I was falling to pieces on that hospital bed.

[Self-
negotiation]

[12] The evening passed, the night came, the next morning arrived. As morning broke, I had to make many decisions. Did I have time to act upon them? I did not know.

[Patient-doctor
communication]

[13] The time for the medical examination came. The department doctor, the head physician and the surgeon stood around my bed with enlightened faces. The surgeon told me about the surgery: that the melanoma was in the top layers of tissue, that is to say was graded as Clark 1, and so they had to make only some small incision and could then close the wound directly. The doctor told me that I had been lucky. When I went home I was in good shape. To remove the stitches I had to go the healthcare centre if I did not feel like doing it myself.

[Post-recovery
health
condition]

[14] The melanoma checks take place in healthcare centre, at first every six months, when they take a thoracic X-ray. I have been to these check-ups twice but there has been nothing new. My condition is excellent.

[Concerns
about her
grown up son]

[15] The son, about whom I feel so much guilt, got alcohol psychosis in autumn 1993, which put him in hospital. This was a terrible thing for me. I thought that my melanoma is nothing compared to you losing your mind. They told me that my son had been really worried about me. This made him use more alcohol in order to escape reality.

[The
significance of
the help offered
by society]

[16] I totally forgot about myself. I began to follow how psychiatric care is given today. I saw many mistakes. As a result, I had to develop myself. I applied for a place on a course to learn psychiatric care. At the moment I study. I have a lot to do, both on the somatic as well as the psychiatric side. My son is out of hospital and goes to continuation treatments at the psychiatric unit as well as the AA-clinic. I pray that my son has strength, that he will manage in life. Otherwise, my own life is really good.

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