

Evelyne Leandro

The Living Death

or

**The struggle with a
long-forgotten disease**

A diary from today's Berlin



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Contact:
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Anne Kiely, Colchester, UK

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Mike Kiely, Colchester, UK

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Sibylle Cordes & Evelyne Leandro

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CONTENT

Prologue.....	1
Exposed.....	3
Berlin Calling	51
Life on the Roller Coaster	77
Summer in the City	108
Next Stop: Würzburg	134
Cheers to the New Year	167
Rehabilitation	174
365 days later.....	190
Epilogue	194

I forbid you to ever enter a church, a monastery, a fair, a mill, a market or an assembly of people.

I forbid you to leave your house unless dressed in your recognisable garb and also shod.

I forbid you to wash your hands or to launder anything or to drink at any stream or fountain, unless using your own barrel or dipper.

I forbid you to touch anything you buy or barter for, until it becomes your own.

I forbid you to enter any tavern and if you wish for wine, whether you buy it or it is given to you, have it funnelled into your keg.

I forbid you to share a house with any woman but your wife.

I command you, if accosted by anyone while travelling on a road, to set yourself downwind of them before you answer.

I forbid you to enter any narrow passage, lest a passer-by bump into you.

I forbid you, wherever you go, to touch the rim or the rope of a well without donning your gloves.

I forbid you to touch any child or give them anything.

I forbid you to drink or eat from any vessel but your own.

(Mass of Separation. England, 13th century)

PROLOGUE

“Even when it seems that everything comes to a standstill, I have to decide whether to laugh or cry, to go on or to stay put, give up or struggle, because I’ve discovered an unknown path in life, where deciding is the most important thing.”

This sentence from Brazilian poet Cora Coralina has guided and encouraged me as I needed to take the path when I could not foresee how long and how arduous it would be. It preserved my laughter and led me along the path, because I had many decisions to face. Even today, this sentence has not lost its validity; in fact it’s increased. It has been proven and I will carry it with me for the rest of my life.

This book is a memoir, a diary of the past and present and, in a way, I am Cora Coralina, who will tell her story along the course of this inconceivable time.

Firstly, it’s enough to say that I am a Brazilian who had lived in Berlin for more than two years when I was attacked in January 2012 by a disease which nobody expects any more in Europe: Hansen’s disease.

In Germany, better known as leprosy.

From the beginning, I didn’t want to allow this disease to destroy my life or stop me getting to where I wanted to be. Because I wanted to continue my life.

The path is long, painful and sometimes lonely. I wanted my story to be tangible. Something which allows me at some time to close the book and be able to say “I have won!”.

Because, as my uncle wrote to me: “It is not in the playground that we learn”.

Without suspecting that I carried a disease within me, I heard the universe whisper a hint of it to me. I, who always wanted to write a book and had often started something without bringing it to a conclusion, had a brainwave as I saw a wonderful diary in a stationery shop: to write a

book in the form of a diary, about a woman who is interned in a hospital for a few days.

The story would be told from the perspective of the patient, about her feelings and experiences, her problems in adapting, her emotional state, about the people around her, her communication with the outside world, without necessarily putting her illness at the forefront. The illness would merely bring the story about. It would be trivial.

This idea wouldn't leave my head until, two weeks later, I had to discover that the sick woman with the illness was myself. I laughed at the irony of fate, laughed at how the universe had leered in my face. Before I knew that I was ill, the idea had already germinated in my head. And from then onwards, it went no further.

The story, although based on facts, is not necessarily correct in minutiae. Some moments are no longer in my memory and others I have pushed away for understandable reasons, or I have had to gloss over them. Let's name it like this: life after the impact. Everything that happened. Or should I say "providence". To amplify my diary, I will publish emails from my relations and friends, conversations with doctors and some remarks and everything I believe to be necessary to make the situation of the day understandable, but also to arrange the reading to be more pleasant.

It is a piece of me and I want to share it.

EXPOSED

In September 2011 I discovered blotches on my left arm and my right knee and calf. The doctor diagnosed Lyme disease, an illness caught through ticks, which occurs both in Germany and Brazil. He prescribed antibiotics and, in time, the blotches disappeared. I thought no more of it.

Two months later I celebrated my 30th birthday. I was content with my life. I had invited a few close friends to a small party at my home and I remember both their comments about my good mood and the amusing conversations.

I was, quite simply, happy. A few weeks before I had started work in a new company. I was highly motivated because I was working in a large enterprise, which could offer me a wealth of possibilities. My second year in Germany came to an end and I was full of expectations for the coming year.

My husband had warned me when we were in Brazil. He said to me then that the first year in a new country would be interesting and wonderful, when everything is still new and exotic.

In the second year, the crisis came, when the mundane life arrives and, along with it, difficulties to overcome instead of language problems and various cultural norms. According to him, it would only be from the third year that one would gain a foothold.

On that day, my 30th birthday, I felt full of energy, ready to get going again. I didn't suspect that two months later the greatest nightmare of my life so far would take its hold.

In the first week of January 2012 the blotches returned. They were larger and my left elbow was painful. The doctor suspected erysipelas, also called St Anthony's fire or cellulitis. I took more antibiotics. They didn't work - of course.

Without any improvement in the symptoms, I was admitted to a dermatology clinic in Berlin for further investigation.

Here my story begins. The disease is not in focus. But everything that has happened in my life since then.

The day before

I had to go to a follow-up appointment to see whether the antibiotics had taken effect. At work, in the bright light of the toilets, I noticed blotches on my face which had not been there previously.

On that afternoon I had two important meetings at the company. I didn't know what I should do. My arm was painful. Was it more important to participate in the meetings or go immediately to the doctor? I decided to take part in the meetings, to go home after them and still try to get to the doctor.

I was in a panic. The new rash on my face gave me great concern. How could something develop so quickly? Practically overnight.

In the subsequent hours my panic increased and I went to my boss, who sent me straight home. I went home crying. I could no longer control my tears. I didn't know what I had. I didn't want to miss these important meetings. I wanted to meet my husband so that he could calm me down. I remember that I called him, weeping, in the hope of a solution from him, which of course he couldn't give. And I had absolutely no idea what could be wrong with me.

When I arrived home, I rang my doctor, who could only give me an appointment for the next morning. I decided to sleep to clear my head but my panic was overwhelming. I knew that something very wrong was happening. I felt it and it began to disturb me deeply. But on that day, at least, there was nothing more I could do.

Day One

The next morning I went to the dermatologist. Nothing had improved; quite the opposite. The doctor admitted to me openly that he had no idea what this could be and referred me to a hospital. He said that they would be able to diagnose my illness there.

The consultation hours at the hospital started in the afternoon, so I went home first. The doctor had advised me to stay in the hospital for a few days. That meant that I had to pack my bag with what I would need. I reckoned with four days, until the weekend.

The prospect scared me. I had never been in a hospital for any length of time. And in Germany! Medical problems are much easier to explain in my mother tongue.

With my bag packed, I sat on the bed, waited for my husband and cried. What awaited me? What did I have?

I had researched all the likely skin diseases on the internet but had found nothing which could convince me that what had happened to me was a “normal” disease.

The hospital was on the other side of the city. We arrived at 2.30 pm. Whilst we were waiting to be called, a thousand things went through my head. The disease itself didn't worry me so much. What worried me was the lack of information, this dreadful uncertainty and the fact that I had to go to a hospital to find out what I had. At least my husband was by my side. His presence calmed me during the hours which passed so slowly.

Just before 5 pm I was called. I entered the senior consultant's room and outlined the situation to him. He couldn't tell me what it was either. He doubted some of my information. From the start, his arrogant manner grated on my nerves.

He wanted me to return in the next few days for various examinations. However, I wanted to leave the consulting room with an answer. And if it had to be, I would stay in the hospital. I didn't want my condition to deteriorate because I had realised that even more new blotches surfaced on my body as time passed. I was completely confused by the lack of clarity. I insisted on a medical opinion.

Finally, after lengthy discussions, it was decided that I should stay in the hospital and the investigations would start immediately.

Around 8 pm I went into the room which would be my home for the coming days: tired, sad, bewildered and lonely. My husband went home to the children.

Eventually, the night sister calmed me. She greeted me with a smile and tried to make my night as pleasant as possible. She brought me a drink of hot chocolate.

Over the days, my arm had become inflamed and the rashes on my legs had multiplied.

Because of my “neighbour” in the next bed, I had to get myself together and couldn’t weep openly. There would be more opportunities later and better reasons for it.

It was 24 January 2012.

Day Two (25 January 2012)

I woke completely distraught. From a loudspeaker I heard something or other in German. I was in such a state that I could not understand a single word.

I had slept badly: in a strange bed, in a room without curtains, repeatedly woken by the blue light of the ambulance. Nurses had from time to time come into the room, turned on the ceiling light to see I knew not what. I reckoned that I had slept for four hours at the most and, for me, sleep is such an important part of the day.

Two women doctors came into my room early in the morning. They thought that I had two unrelated problems which had occurred at the same time. One was the disease itself and the other a reaction to the antibiotics I had taken. I tried to explain to them yet again that the rashes had appeared before I took the antibiotics. But I was also sad to have to constantly retell the same story. In less than two days I had to repeat the story five times.

Later, the senior consultant came on his rounds with other doctors. They decided to take biopsies for testing from my right arm to identify the bacteria. I can’t say whether I was pleased about the fact that they were going back to basics, or sad that they were going to give me more pain than I already had.

In the afternoon the biopsies were taken: three small pieces of flesh from the patches on my right arm.

I liked the young woman doctor. She was very sensitive and tried to make the situation as uncomplicated as possible. The most important thing for me was that she explained everything: the doctors' theories and the next steps. In contrast, a normal conversation with the senior consultant was impossible. He was the omniscient man and I was the foreigner from the deepest Amazon forest even though I had never been there. One of his questions was whether I had ever been in the forest, eaten wild animals etc. When I denied this, he looked at me as if I had lied to him. At least he had considered whether I had a "serious" illness.

From this day onwards I became continually more nervous. I waited very impatiently for the results of the biopsies. To me it was clear: the quicker the diagnosis arrived, the quicker the treatment could begin.

I had been in the hospital for less than 24 hours and absolutely wanted to be at home.

E-mail to my mother

Dear Mum, how are things?

I'm writing to give you some information about your little Miss in Germany.

In September last year I had a skin problem, with some patches on my body. I went to the doctor and he said that it was bacteria. I took medicine and the patches went away.

Within two weeks the patches came back and this time more intensely. On my left arm a large, coloured, painful area appeared and also rashes on my legs, calves and feet.

I went back to the doctor but he couldn't tell me what I had and referred me to a dermatology clinic for further investigation.

But even there the doctors couldn't say what I had. Result? They kept me there and since Tuesday I have been in the hospital and have to stay here until they have a diagnosis. Apart from that, I am well and the patches (and also the pain in some parts) are less. Because they dry out, I always have to scratch. You know well how crazy that makes me :)

I didn't really want to share this with you by e-mail but I don't know whether I will be at home this weekend to phone you.

The doctors already have an idea what it could be but they are not sure. So, they are investigating further and testing different ointments.

Apart from that, the irritating thing, apart from the fact that I am in hospital for the first time and don't have my Mum here, is that the bed is impossible and I'm sleeping really badly. Otherwise, the staff are really nice and they pronounce my name well. In Germany, people usually just have an ordinary surname and they find "da Silva" very noble. Funny! If they only knew that it's as common as Müller, Meier, Schmidt is here...

I am OK, I just need a little TLC.

Kisses... I love you. Your little Miss.

Her reply

My dear daughter, how are you?

Are you feeling better today? Are there already results from the tests? We are worried and I'm sorry that we can't be with you, but we already knew that. I hope that all will soon be over and that you can continue the treatment with your husband at your side. OK?

Trust in God that He will grant you the serenity to accept the things you cannot change, courage to change the things you can and the wisdom to know the difference.

Your father is at home and also concerned and sad. But that's normal, given the great distance and the feeling of helplessness which weighs on us.

Soon I will have the internet and then it will be easier for us. I will share it with your uncle and have already been to acquire a computer. Don't be knocked down or desperate about your first stay in hospital. There's always a first time, isn't it?

Without wishing it, the thought has occurred to me that the symptoms are those of leprosy aren't they? If that's so, don't worry because there everything will be treated more quickly and efficiently than here, whatever it is.

God's care is great and his compassion endless. Trust and all will be easier. Continue as you are, good daughter. For Him and for me. OK?

An embrace full of love and many kisses for you. And don't forget that Jesus loves you and so do I.

Your crazy Mum ;)

I am the daughter of a long-distance driver and a housewife. My father only attended primary school and can only read and write a little. My mother had a job as a secretary in a factory which she gave up to marry and to move to the more developed south of Brazil. I came into the world there in 1981.

Three years later my brother was born. When he was six months old my parents decided to return to Bahia, to be close to their family. Bahia is a federal state in the poor north-east of the country which is also called the "Africa of Brazil". They still live there today.

In Berlin things were much the same. The doctors seemed not to know what to do with me. But I also thought that they weren't 100% honest with me. I had the impression that they had a suspicion but didn't want to talk to me about it. Either because they were not yet sure or because they didn't want to put me in the picture yet.

I remember that I mentioned the hypothesis of leprosy myself. I had had comments from two different people who reminded me about the disease. One was my mother. I ran this possibility by the senior consultant. He asked me whether I could remember having contact with someone infected with leprosy, which I denied. Truthfully, I could not remember such an occurrence. I knew no-one in Brazil who had leprosy and certainly not in my circle of family and friends. He ruled out this hypothesis. I noticed however that he simply wasn't being honest. I saw the looks he exchanged with the women doctors.

Sleeping was too much for my head to cope with, in the knowledge that I had a severe illness as well as the sight of the rashes and the pain in my body and the uncertainty of the doctors.

I also began to think of the unknown length of time that I would have to stay in hospital. I thought of the things which I had left behind. And of

what I might lose. The longing for home and all of the hopes which I had built in the last two years of my life in Germany.

I had believed that this third year in Germany would bear the fruits of my hard work. The year which would give me the certainty that my chosen path was the right one. The year when my efforts would come to fruition, when my decision to start something new would be confirmed. I thought of my work and what I still wanted to achieve.

But I felt lost, physically and emotionally tortured after all of the investigations and the unanswered questions. The doctors' uncertainty made me uncertain. The diagnosis should have been there for a long time. Then on Friday it came.

And from then my story really begins.

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