

TWO EMPTY CHAIRS
AIDS: CLOSER THAN YOU THINK

HAN NEFKENS

Translated by Nancy Forest-Flier



If you haven't got HIV yourself and don't know anyone who does, it's easy to dismiss AIDS as something far away. The simple fact that for so many people AIDS is something "far away" makes the battle against AIDS that much more difficult, because whatever is far away can easily be forgotten.

The figures seem to speak for themselves. More than forty million people around the world are living with HIV, the virus that causes AIDS. More than three million people die of AIDS-related diseases annually, and the figures are rising every year. But the figures don't tell the whole story - the story of women and children who are the hardest hit, the story that more than 90 percent of the people in developing countries who are infected with HIV live without effective medicines, the story of misery, grief, banishment and loneliness.

Han Nefkens lives with HIV. In his columns about HIV collected in this book he helps the reader understand exactly what this means. He shows us how HIV infects not only his body but also his day-to-day existence, how it sometimes turns his world upside down, but how it also makes him aware of what's special ... in people and in art. He goes one step further, however: he seeks face-to-face contact with people in developing countries, people for whom no treatment is yet available, for whom HIV is still a death sentence. In establishing that contact he makes the gap between the West and the developing countries painfully tangible. For him, AIDS is not "far away," neither from his own life nor from the lives of the people he meets there.

By allowing us to witness the fierce emotions and intimacy of those encounters, he builds a bridge between living with HIV "here" and living with it "there," and in doing so he brings AIDS a bit closer. At the same time he denounces the gap between rich and poor, always challenging the reader to come up with an answer to the question "How far away *is* AIDS, anyway?"

Peter van Rooijen, director of the AIDS Fund

1. False positive

September 24, 1987. Calle Durango, Mexico City.

It was a busy day for me. I had to write an article on a leaking nuclear power plant and buy a pot of honey at the health food store on the corner. And I had to pick up the results of a blood test from a private laboratory.

For months I had had an infection in my throat. I had been to several specialists and had taken several kinds of antibiotics, but my throat was still red and I was still coughing. I was sure it came from the air pollution, that brownish-yellow blanket of smog that hung so heavily over the city.

A friend of mine, a Dutch homeopath, had casually suggested that I have an HIV test taken. I wanted to know if that was the same as the AIDS test. I had been involved in a steady relationship for several years, so my chances of being infected seemed minimal. Kees, the homeopath, agreed that the chance was small, but you never know. Kees wore sandals, and I had never had much faith in the opinions of people who wore sandals.

At the laboratory the receptionist handed me an envelope, which I opened when I got out on the street. The report said: *anti-cuerpos antígenos HIV- positivo*. Did positive mean negative? Did positive mean in a couple of years you'd be dead?

I stood in the middle of that busy street in Mexico City. Cars raced past me, pedestrians pushed me from behind, daylight began to fade. I decided to go back inside and talk to one of the doctors. After many urgent appeals I was finally able to speak with someone in a white coat. The doctors had all gone home. This was the son of the lab owner, who told me that there was a 10 percent chance that this was a false positive result.

He advised me to go to the United States and have a test taken with the most modern equipment. That test would be conclusive. When he wrote the name of the test on the paper containing my unreliable results, I wondered if he had spelled it correctly. Was it really a Western Blot test I had to get or a Western Blood test, something meant especially for me and other Westerners?

Back outside on the street I calculated that if there was a 10 percent chance that the results of this test were incorrect, and you had a 50 percent chance of getting AIDS if you're HIV positive (as I had recently read in the papers), then I had a 45 percent chance of being dead within two years. Or was it 47.5 percent? I've never been very good in math, and I wondered if there was any point in learning now. I held the pot of honey so firmly under my arm that it left a red streak right above the place where the blood had been taken out of me by the same lab ten days before.

One week later I went to America. The test was indeed the Western Blot, not Blood. And sure enough, my blood was quite infected with HIV. In Houston they told me it was important to have my "T-4s" checked. When repeated tests over a few months showed a steady drop, they put me on AZT. I had to take one pill every four hours, so I bought a pill box at a big shopping center along with an alarm clock that also went off in the middle of the night.

I've tried them all since then, the pills and the cocktails. Thanks to all that ingestion I've managed to stabilize my T-4s to keep the virus at an undetectable level.

But what if I had been a real Mexican? A Mexican who didn't have the money to fly to Houston for a Western Blot? A Mexican who didn't have the money to pay for AZT and DDI and Kaletra and all the combinations ending in *-vir*? Who received the same results on the same evening and read them there on the street in the dwindling

daylight, just like me, quickly tearing them up and trying to forget them because he couldn't do anything about it anyway. That Mexican - those tens of thousands of Mexicans - are now dead. Is it just lucky that I have Western Blood, and Western money? It that it - a matter of luck?

Did I luck out?

2. My own medicine

“False Positive,” the piece I wrote last week, traveled to Mexico and has just now made its way back. A friend of mine, who lost her brother to AIDS several years ago because there were no medicines in the hospital in Mexico City, wrote that when she read what I had written she broke down and wept.

“But I also realized how privileged I am that I’m still alive. I realized the enormous responsibility I have to live every minute to the best of my ability. I’ve been given the chance he never had.”

In those few words she captured just what I meant. She gave me a taste of my own medicine – of our own medicine. It’s something I have in my mouth all the time but seldom taste. I allow myself to sink into the cares of daily life: the socks that have to be washed, the appointment I don’t want to miss, the bedspread that needs to be straightened, the cap on the tube of toothpaste that has to be screwed back on, the turnips that have to be cooked – ordinary life. But ordinary is not ordinary. Ordinary is extraordinary.

I get treated to a demonstration of how extraordinary the ordinary is three times a day with every dose of medicine I swallow, and all I want to do is forget about it. I’m too busy negotiating the price of a new painting, applying my moisturizing cream, re-organizing my wardrobe to make room for more striped shirts. I worry whether my new shoes will look good with the jacket I bought last week.

I – who ought to know better – am so busy with ordinary life that I don’t realize how extraordinary that ordinary is.

I rarely taste my own medicine. Sometimes I run my tongue over my palate, but I tend to swallow it right away. I only really taste my own medicine when it’s so big and overwhelming that I can hardly get it down. Like the e-mail medicine I got from my friend in Mexico.

3. Mercy Centre

It’s not difficult to meet people here in Thailand. A friend introduced me to someone who, like me, is a writer. We’ve got even more than that in common, I thought, when I saw that Tew was wearing the same glasses I was. He also has a house near Barcelona so we spoke Spanish together on the way to Mercy Centre, the little hospital where people with HIV are cared for, located in the middle of the Bangkok slum.

Tew is there every day, so he knows everybody. His movements are as free and relaxed as mine are stiff and awkward at seeing people with whom I have so much in common except for the fact that we were born in different places. Most of them are lying in bed and waiting. The image from the past that we struggled to erase from our memories still exists here. On one bed there’s an old man hooked up to an oxygen machine. Coming closer I see that the man isn’t old at all; he’s younger than I am. Tew thinks today will be his last day. He strokes his arm and whispers something in his ear. I look the other way, where I see a young girl with wide-open eyes. She’s beaming, but she can’t see me. The virus has affected her brain and recently she went blind. I brush her hand and she gently squeezes back.

In another room children are playing. Because their mothers were given medicine when they were pregnant, some of the children have developed a resistance to HIV inhibitors; they often don’t live past the age of twelve. The children who are too weak to go to school watch cartoons on television. I sit with them, give one of the boys some fruit juice and stroke the back of a girl with a rash on her lips. What do you bring for children with HIV? Candy? Ball point pens? Teddy bears? Crixivan?

An attractive woman walks around with a T-shirt bearing the word “Police” in big letters. In a few weeks she’ll be strong enough to go back to the Super Pussy Club in Patpong to earn some more money

for her family. “What can I do?” says Tew. “Tell her she can’t go?”

I suggest that she take a big bag of condoms with her. But Tew says many clients won’t use them. The girl is young, she looks good and the men are far from home in an exotic country.

A woman is brought in by her father. She has an open wound on her buttocks and he doesn’t know what to do for her anymore. She’s carrying her belongings in a plastic bag: a blouse, a cup, some photographs. She puts the plastic bag on the bedside table, sits down carefully on the bed and looks around. When her father says goodbye and walks away she waves at him and keeps on waving, even long after he’s disappeared.

What I really want to do is sit beside her on the bed to keep her company and keep myself from feeling so alone. But I walk on. It’s an instinct; I can’t help it.

In the next room a critically ill person is being massaged by a volunteer wearing a mask to protect him from TB. My Thai alter ego with the tasteful glasses says hasn’t worn a mask in a long time. He’s not afraid any more. I’ve got a lot to learn from him.

I smile at the woman on the bed, and she laughs back as Thais always do, a laugh that can mean a thousand things and that we foreigners cannot understand.

In a month I’ll be back, because despite its dreadful name I belong here in Mercy Centre. We all do.

4. Press release

Associated Press - Blantyre, Malawi. A prominent tribal chief from Malawi denied the existence of AIDS on Friday and said that the thousands of people whose deaths have been attributed to the epidemic actually died of a plague sent by God to punish young people for misbehaving. “Contrary to what the government and other people maintain, there is no disease called AIDS in this country,” said Group Village Headman Makunganya to journalists and officials of the Malawi Human Rights Commission. At least 14 percent of the 11 million Malawians have HIV, the virus that can cause AIDS but what Makunganya said is a conspiracy dreamed up by activists to confuse people.

For all those years I thought I had a virus in my blood, but I was totally wrong. It’s all in my head. It’s a plague sent by God. A conspiracy dreamed up by activists. That’s certainly put my mind to rest. Now I can throw away all those nauseating pills. I and the one and a half million Malawians can just flush them down the toilet. Except those one and a half million Malawians - not to mention forty million other people - don’t have any pills yet to flush down the toilet.

Maybe all of us should first make sure that they get those pills so we can flush them down the toilet together. So that together we know there’s nothing wrong, as long as we behave ourselves. If we behave ourselves, no plague or conspiracy will ever bother us again. Then we won’t need any pills. All we’ll need is a clean conscience and a good head on our shoulders.

5. Day-night

Abruptly awake at five o'clock in the morning, I find the world around me empty and still. It's been quite some time since I made a deal with myself to stop pretending I'm asleep. I can't do it anyway, and there's nothing so embarrassing as a bad imitation.

The thoughts of an insomniac and the dreams of a sleeper are both the same. You get swept along, and you're never given the chance to choose between a pleasant dream or a nightmare, a nice idea or an image of horror. The beauty of dreams is the just like horror of nightmares: no matter how hard you run you never make any progress, and like the worst moments in your life you find you have no control over events.

Every night I wake up with a picture in my head. So I silently slink to the computer in my bare feet and try to work the wet, shapeless clay of that picture into some kind of shape. I knead and push and pull without any attempt at reflection. My lower appetites take over and lead me on, as lower appetites often do at night.

I'm always surprised with what comes out of that mass. Maybe it's the urge to surprise myself that wakes me up in the first place. If I already knew where I was going to end up I wouldn't have to sit down at my computer any more. It has to do with things that are hidden, thoughts that emerge from the clay. With my clay I'm never alone.

Eventually my night turns into day – a night-day spent sculpting. Sometimes, when the mass refuses to take shape and I don't have any company, the silence is overpowering.

At that point my consolation is the buzzing of the internet. Someone comes to keep me company. A friend from California, where it's late afternoon. An acquaintance in Thailand who's just had breakfast. Then I'm reminded that most of the world is not asleep, that there are people who are thinking about me, so I'm not alone. I like

to be consoled, even if it's by means of a message lost in the ozone, an unwitting e-mail that, thanks to a virus, has gotten through to my hard disk.

If the bell doesn't ring, I look out the window to see if there's a light on in the apartment on the other side of the patio. It could be a light from someone who's just come home from a night on the town, or someone working the night shift. Maybe it's a neighbor who's fallen asleep in front of his television; maybe he just forgot to turn out the lights.

If the light's still on after half an hour it's proof that a fellow amnesiac is living there. If that's the case I can watch for hours. The light on the other side of the patio warms my cold feet.

Only if I see this sign of life do I know that I really exist.

6. Talk about lucky

A year and a half ago the lady sitting next to me at a sidewalk café started shaking badly. The little table shook, her chair shook, the ground shook, the city shook, everything shook. It kept on shaking for three months, and when the shaking stopped I found I was someone else.

I'm not exactly sure what happened during that attack of encephalitis. When I could hear a little of what people were saying again, I discovered I had given them quite a shock without really intending to. Very slowly something began to dawn on me. Something. I don't let everything dawn on me, because everything is still too much for me.

I bumped into an acquaintance recently who patted me on the back and said, "Talk about lucky!" He meant lucky I wasn't dead. He's right, of course, but I don't feel lucky. There's a sadness that still gets in the way, cunningly disguised and hidden. I close my eyes, but it's still there. Sadness, confusion and anger is what I feel, but not lucky. This shows that there's really something wrong with me. I'm sad because my life was in danger and the people I loved were worried about me. I'm confused about what's there now and what I still have to go through. I'm angry that something was almost torn from my hands and then given back, uninvited.

Uninvited, that's why I'm angry. Life has a hell of a nerve, death even more. It just does what it likes, it giveth and taketh away, and can't make up its mind. It was a dictatorship; nobody asked me anything. (Not that I was in any shape to answer questions.)

Seen from that angle life was very sensible, an enlightened despot. Enlightened yet outrageously domineering, which is quite out of place in this day and age.

So I should talk about being lucky while I'm stamping my feet with rage. I'm stamping my feet like a little kid. I'm bawling like a

toddler in the body of a middle-aged man.

The sentence *talk about lucky* is rather long for me, anyway. I still have trouble with long and many. I can talk. About lucky. And about a few other things as well. I really *can* talk. Again. And that's lucky.

7. Role model

I always used to get a little tense before going to the HIV doctor. What if my viral cargo has increased? What if my T-cells have dropped? What if they discover that my current medicines are no longer doing the job? And what if the next medicines don't do the job either? What if nothing does the job and all hell really breaks loose? This is what I used to think while sitting in the waiting room.

Ever since all hell did break loose in my brains, and has now returned to a state of relative calm, I'm no longer tense. The thought "what would happen if..." no longer runs through my head. "What if..." is a much too complicated linguistic construction, far more than I can manage right now.

So I sit in the waiting room and leaf through magazines. I look at the photographs of artists and their swimming pools, and at the glittering jewelry of their ladies.

I wonder why there are always such old magazines in doctors' waiting rooms. Are we unworthy of this week's *Hola*? Are doctors' waiting rooms just wastebaskets where their wives can dump their dingy gossip rags? Are we the next in line for this dirty, thumbbed-through pulp?

When I get the results I don't think, "What if these good results only last three months?" I don't think, "What if these good results only last three years?" I still can't think in terms of "what if" constructions.

When I get the results I'm happy. Just happy. In that respect I'm starting to resemble our dog. I am what I am and nothing else. I'm angry, sad and happy, with every fiber and every muscle of my body. That's it. No nuances, no qualifications. I'm not up to that yet.

Who knows? With a bit more practice I may start looking more and more like my role model. I've still got to work on the burping and farting, and my snout isn't flat enough yet, but that's just a question of

8. Conceptual art

I'm not writing any more. I've had it. All I do is repeat myself. I tell the same story over and over again, thousands of times, but not with thousands of variations. Writing is too closely connected to something I'm fiercely opposed to: reading. I can't be expected to contribute to something I loathe, can I?

Even if I promise not to read what I write, writing remains a vile occupation. It's like a non-smoker working in a cigarette factory. And what's worse, I'm not a non-smoker but an ex-smoker. So this is my last piece. This is my swan song. For today.

Starting tomorrow I'm going to concentrate on my version of conceptual art: I think of something, other people carry it out and I call it art. Actually it's not much different than the way my life has gone so far, except now I'm giving it a name. That makes it look like I'm doing something. Doing nothing becomes doing something. And that's a very attractive idea for a quasi-sluggard like me.

So for the time being I'm too busy doing nothing to write.

The first thing I'm going to do is build a wall of anti-HIV pills. I take an anti-HIV pill (an orange pill, because it's colorful) and put it in a square glass box that measures five by five centimeters. Or I put it in a box measuring ten by ten centimeters. I've got to think some more about which of the two sizes I'm not going to use. It can be a Plexiglas box or something transparent.

I do this nine hundred ninety-nine times. Then I take the thousand minus one boxes and build a wall. A wall to keep out HIV. An anti-retroviral barrier. It's a project that only we in the rich countries can carry out. They don't have anti-retroviral pills in the poor countries. It's not good for them. If the poor countries had anti-retroviral pills there would be too many people there. Of course there are enclaves of rich countries inside those poor countries, where people live in houses

surrounded by stone walls topped with barbed wire. But those people won't want to have anything to do with my conceptual project. That would draw too much attention to the fact that they're ambassadors of rich countries - they represent us.

When I consider building such a wall, and realize that most of the people in the world can't, I get angry. Not sad. Angry. It's so unnecessary. It's just a question of organization. All you have to do is give some thought to how you're going to tackle it so everyone is satisfied, both the makers of the pills and the ingestors, and usually they're not the same people.

And that thought is not conceptual art because it's something that really has to happen. Not tomorrow but today. Now. Doing nothing has to become doing something. This art has to be more than just an idea.

9. To be answered

Il live in Cambodia and my son got AIDS.

The drugs are really expensive.

Any body knows a wat to get cheap drugs from India or Brazil

Thanks

Nissai

Today I received this e-mail from a total stranger. It was buried under the torrent of messages I subscribe to with information about new anti-HIV drugs, side effects, conclusions of congresses and results of studies. It's from a mother (or is Nissai a man's name?) who, like so many other powerless people, is forced to watch her child die a slow death. A powerlessness that is exacerbated by her knowledge that somewhere else there are medicines for sale that can prolong her son's life.

My first impulse was to drop everything, put together a package of medicines and send it to Nissai. I wanted to do the same thing not long ago for people in Mexico, but the Mexican experts advised against it. Helping just one or a few infected people would be cruel for all the others, they said. It would lead to enormous problems among the infected people themselves. Better to contribute something in a structural way, I was told, to a project that makes sure the medicines really end up with the right people, and that they are taken on time and under the proper conditions to avoid resistance.

Is it ordinary human concern that makes this message so touching, so that even the minor grammatical and spelling mistakes move me? Or is it recognition? Because I, too, have been forced to watch as someone I loved die before my very eyes (except he didn't want to take the medicines that were available to him). Or is it survivor's guilt? I'm saved, they're lost.

There's absolutely no acceptable reason why I should be allowed

to prolong my life while tens of millions of others should not. I haven't done my best any better than they have. I'm not more worthy of life than they are. I was just born in the right place and in a good environment. Unlike those tens of millions of others I've had all the luck. Dumb luck.

So should I spend all my money on a project to make medicines available to people with HIV in the Third World? Is it decadent that I buy works of art by Roni Horn and Joerg Sasse, that I stay in the Oriental Hotel and shop at Prada while people are dying of the same disorder I have? Or should no one, including those who are not infected with the same virus, be allowed to buy more Roni Horns and stay in the Oriental Hotel as long as there are still people needlessly dying on this earth?

Is this survivor's guilt? Do I think I should pay a price for the fact that I'm still here? Should I do penance? Or, worse yet, am I secretly making a deal in the back of my head with a higher power: if I give away all my money now to help others you've got to let me live, because fair is fair. As if I didn't know that fair isn't fair at all in this life, and that there is no higher power to whom we can turn with our petitions and promises, with concealed attempts at bribery.

Nissai turns to the world in general via the Internet. She turns to me. I store her e-mail in the archive for messages that I don't know how to respond to but don't want to erase. No, better yet, I open a special archive for her: Nissai, to be answered.

10. AIDS Memorial Day

Generally I don't think about them very much any more: Jeff, Mario, Julio, Carlos, Pedro, Pascal, Francisco. Victor is the one I think about most. I don't like to think about the past. I prefer to focus on the future. I've got to go on. It's pointless to reflect on past events - pointless and far too painful.

That's why I hate AIDS Memorial Day. It forces me to cast my mind back, while I had gotten so good at forgetting them.

When the day comes I feel the grief once more at being cut off, the shock that the unthinkable really took place and that no one is safe, no matter how carefully you hide. I feel the anger again because life abandoned them. I feel the almost paralyzing fear that I'll be next.

I remember that whenever I went to the cemetery I'd suck the cool outdoor air deep into my lungs and firmly tell myself: you're still alive, they won't get you six feet under.

I try to let go of Jeff, Mario, Julio, Carlos, Pedro, Pascal, Francisco and Victor. I cling to their lives, press them so hard against me that they leave marks in my skin, scars I'm happy to have because I've still got time and they don't.

Even so, they keep coming back. Always unexpected and certainly uninvited, they occupy a place in my life. Suddenly I hear the deep voice of Jeff, who makes jokes about the other members of the support group he faithfully met with every Thursday night. I say the words again that Mario and I thought up together, our own language that now I must speak alone. I lay my cheek on his belly once more and take in his scent - strong yet sweet, familiar. I look out over the roofs of the city from Julio's terrace. He serves me a piece of birthday cake with twenty-eight candles, the most there will ever be. I see how the light falls on Carlos's hair as it curls slightly over the top of his collar, and I can't resist stroking it just once. Pedro reads to me again from

a newspaper article about a new medicine that he's sure will do him wonders. I hear his mother softly crying as she touches his coffin for the last time. I walk past the place in the city that Pascal had shown me with such pride; he knew every hook and cranny, and now I do, too.

I embrace Francisco in the twilight. He's not the one for me, but no one can see you in the semi-darkness so it doesn't count.

I saw Victor just last week in the Bijenkorf. I turned around and chased after him, up the down escalator, but he was already gone. I see him in the metro, on an advertising poster near the airport, on a terrace wearing big sunglasses that he thinks he can hide behind, in a home movie from thirty years ago, the two of us fighting for our mother's lap.

I hate AIDS Memorial Day. I don't want to think about the past. I'm focusing on the future. I've got to go on.

11. Anonymous Clinic

T. had called the hotel, and the head of the bellboys had spoken with the man from the taxi service. We had to go to Snake Farm, he said.

At first I was afraid it was just another tourist trap where you suddenly find yourself stuck like a rat in a maze. But T. knew what we had come for, and surely she wouldn't send us to a tourist attraction. We're *farangs*, though – foreigners - not Thais, and when it comes to foreigners you can only guess at their idea of fun.

The taxi crawled through the traffic. We passed a sign that said *Anonymous Clinic*. Must be something for alcoholics, I thought, people in denial who want to keep their secret from getting out at any price. Fifteen minutes later we were back at the corner where the driver had made his turn, and we stopped at the sign for the Anonymous Clinic. This can't be true. We, in our gleaming limousine from the Oriental Hotel, are not here to visit this underground, half-camouflaged place known as the Anonymous Clinic. But it was true. The Anonymous Clinic is located in a part of the city called Snake Farm. It's the clinic where Thais who are HIV positive come for treatment, where they get their medicines and see the doctor. The project is supported by Dutch and Australian physicians, and that's why I wanted to see it.

It was a hospital like any other, no different from the countless hospitals I've known and visited in all the countries I've ever lived in. Except in those countries they don't call it an Anonymous Clinic. To call something "anonymous" is like putting on five pairs of sunglasses at the same time and wearing a big sticker on your back with the words I AM INCOGNITO, DON'T MIND ME in red letters. If anyone still fails to notice it won't be long before they do. Why isn't it just called the Pajurakran Clinic, or the Bangkok Clinic or the Thai Clinic in Thai?

T. gave us the friendliest of welcomes. She told us that about fifteen hundred people come to the clinic from all over Thailand. Some

have spent the entire night in the bus. (And I complain if I have to get up early for an eight o'clock blood test.) T. shows us the medicines the people there are given. They're exactly the same as the medicines I take, except one. It's brand new, and we don't have it yet. It's reassuring to know that the people in Thailand take the same stuff I do – reassuring for them and for me.

Whenever I visit a country for the first time I have this almost compulsive fantasy in which I imagine I'm living in that country for good. So I look for an apartment where I can live, invent a place of work and try to imagine what my daily routine would be like.

It's a fantasy that's easy to indulge in Bangkok. I've already found the apartment – it's in the center of the city – and I'd take the medicine I'm taking now except for the one I don't have yet, which I'd add. It's a good thing we've already found the apartment because I wouldn't like living very far from Snake Farm and having to spend the whole night in the bus.

But if I were a Thai, a real Thai, would my family know that I go to the Anonymous Clinic? Probably not, otherwise the clinic would have been given a real name. If I were a Thai, a real Thai, would people know I'm HIV positive? Probably not, because Thais are like Mexicans – they don't like disagreeable things. You've got to make sure you don't talk about disagreeable things or you'll get treated to some disagreeable things yourself. If you try hard enough to keep quiet the disagreeable things go away on their own. But HIV only gets worse the longer you keep quiet about it.

If I were a Thai, a real Thai, would I keep on imagining what it would be like to live wherever I happened to be, or would my fantasy go no further than what I know? And would that be enough? Would it be more than enough?

12. Monopoly

Note paints yellow clouds, purple sky and orange trees in an enormous garden – everything that’s far away from the slums of Bangkok where he grew up. He depicts the world as he’d like to see it – a life without sickness, with an enormous red sun. But Father Joe says the HIV-infected children at Mercy Centre never live past the age of twelve. Their resistance is often broken down by malnutrition and the virus by the time any medicine gets to them.

Most pills come in adult dosages; these are broken in half and the contents are dissolved in water. But medicines meant for adults don’t always work as well in children. Children are also more troubled by serious side effects, and the pharmaceutical combinations that the Thai government makes available to children with HIV free of charge are not as effective as the top-of-the-line therapies we get in the West.

Note’s health is precarious. According to Father Joe he has maybe a year to live, two at the most. I wonder if Note can understand English, and I suspect that even if he can’t he knows what we’re talking about. Last week one of his friends died.

Note conjures up an enormous blue airplane on the canvas, where four blank meters await him. I want Note’s paintings to acquire a prophetic power. I want him to keep on painting, and I promise him a chocolate bar at the end of each week and a Monopoly game when he’s finished. That Monopoly game is what he’s dreaming of: an imitation world where he has a chance of winning.

Father Joe invites me to stay for lunch. Today there’s a treat in store for Mercy Centre: a rich gentleman has given a party in a chic hotel, and his chauffeur has brought over all the leftover food. One of Father Joe’s assistants carries the big boxes filled with petit fours, roast chicken, potato salad, rice, canapés and a gigantic chocolate cake

to the assembly hall where we’re eating. The name of the hotel where I’m staying is printed on the bags. Ratana gives me a piece of omelet; I estimate the party took place at least three days ago. Father Joe tries to guess whether the dish that looks like a classicistic palace is sweet or savory. I recognize it. I had it yesterday in the hotel’s Italian restaurant, but I don’t say anything.

As I slowly make my way through the cold omelet, I see a boy of about nine help his friend, who can’t walk very well any more, to get to the toilet.

That very afternoon I decide to buy more chocolate bars at the Western supermarket near my hotel. Forty thousand chocolate bars – a thousand for every child at Mercy Centre. And that’s just for starters. We’ll see how it goes from there.

13. Hearty soup

For fifteen years the virus was snapping at my heels until it finally caught up with me three years ago and settled in my brain. As the uninvited guest feasted on my gray matter I could hardly speak or think, let alone read or write. I could no longer walk or eat without assistance. Two nurses had to support me when I went to the bathroom. Everything going on around me pretty much passed me by, and it looked as if I'd really come to the end of the final act, although I myself was firmly convinced that what I was watching was still the curtain raiser.

A miracle, in the form of the right combination of medicines, turned the entire incident into a badly timed, overly prolonged intermission, and after three months in the hospital I started out on the toilsome road to recovery. Every now and then I decided it was time for all this business to be over and I'd do a failed imitation of stepping out briskly into the street. Within a few seconds I'd lose my balance and end up flat on my face. While lying on the ground I cursed the sidewalks, which were too crooked and had turned the world into a big playground slide.

When I finally allowed reality to dawn on me I found I was in for a big shock. I realized that the encephalitis had ruthlessly pushed into the background all the features that make me who I am. My character, my past, my surroundings, the things I've learned and the things I've never wanted to learn had completely disintegrated. All that was left was a wobbly man, a man who was barely capable of doing anything anymore and had turned into a patient.

Every human being is like a dish of culinary complexity: an Indonesian rice table, a fejuada, a paella. Some of those dishes are pleasing the minute you smell them; others are an acquired taste. And there are also those that you just can't get yourself to eat, even after years of trying.

There are special dishes with mysterious ingredients that you can't pin down. You take a bite and taste shrimp and curry, but you know there's more to it than that. So you continue, pleasurably guessing until your plate is empty and you know only one thing: that was delicious, delicious and special.

When one ingredient gets the upper hand and you can't taste any of the others, the dish loses its appeal. Someone who's only a director, only a mother, only a homosexual, only HIV positive, loses the various dimensions that make people so attractive. You're just a raw onion, an uncooked potato, one of the many onions and potatoes that make up the huge pile.

The terrible thing about being sick is that you're robbed of the dozens of features that make you who you are. For that reason alone there have to be medicines for everyone who's sick or running the risk of getting sick. Not only do all of us have the right to live, but we also have the right to versatility, we have the right to become more than a raw onion or an uncooked potato. We have the right to be an entire dish.

I've been lucky. I just so happen to have been born in the right place and in the right family. That's why I'm back to being a dish with lots of vegetables, big chunks of meat, plenty of fish, a pinch of salt and pepper, a dash of rosemary, a few herbs that you can't quite identify and a splash of cream.

After three years I'm a bowl of hearty soup once again, filled to the brim.

14. The waiting room

Timeless furniture, a withered plant, a faded poster on the wall, a three-day-old newspaper, an uneasy silence – the doctor’s waiting room.

Waiting is being condemned to do nothing. You live in a vacuum between everyday existence and the not-so-everyday that’s now taking shape. You can’t do anything but kill time. I read a book, but whatever I’m reading doesn’t register. I take notes, but my mind is elsewhere. Every activity in the waiting room is a diversionary tactic doomed to failure.

This hovering between two different worlds is a comfortable escape in the airport lounge, but it’s agony in the doctor’s waiting room. There, after the waiting is over you’re forced into another kind of passivity. You’re handed over to someone who gets paid to torture you for your own good, someone who’s able to tell you whether you’re going to spend the rest of your life limping or half-blind – someone who’s able to tell if there’s going to be any rest of your life at all. While the airport lounge is filled with reassuring music, every time I’m in the doctor’s waiting room all I can hear is a lacerating drill.

The scrawny man in his corduroy jacket sitting across from me is pretending to be utterly relaxed, so relaxed that he’s tempted to whistle a little tune. He doesn’t want to disturb the rest of us, however, so he purses his lips and whistles a noiseless tune.

Waiting is whistling a noiseless tune.

You can’t very well talk to the other people in the waiting room about how unpleasant waiting is. If you start a conversation, you let everybody know that waiting is tough on you, that you’re anxious about the unknown that’s just around the corner, that you admit to being weak and vulnerable. This is against waiting room etiquette, where the rule is that we have to pretend we’re not waiting.

The deep sigh, the sigh of waiting, the glance at the watch,

even the complaint, made to no one in particular, that “it sure is taking a long time” – these are desperate attempts to penetrate the sinister silence; they’re veiled invitations to talk. Others in the waiting room – those who are less amateurish, those who have mastered the art of waiting – pretend they don’t hear the silent cry for help. A few of them nod sympathetically, mutter something perhaps, but you’ll never hear a real discussion about how powerless and dependent we feel. That would only serve to underscore the powerlessness and the dependency; it would break the taboo. There’s very little mutual support in waiting rooms; we all wait together, but each on his own behalf.

The waiting room is so alienating that even when we meet an acquaintance there we don’t talk to them in a normal way. We ask them in whispers how it’s going at home or at work, we talk softly, ostensibly so as not to disturb the others. But if that were the real reason, then we’d have to whisper in trams and trains and other public places. We whisper in the doctor’s waiting room because the ordinary world, where we can still have an impact and can still entertain some illusion of control, is banned from this place.

We’ve been handed over to a higher power, just like in church – or in a museum. There’s whispering there, too, and there’s also a higher power in evidence, although usually somewhat less terrifying.

Perhaps these two ought to be combined somehow – art and the doctor’s waiting room. If you’ve got to be quiet, you might as well be quiet for something that can provide a bit of consolation.

Art in the doctor’s waiting room – balm for the sick soul, not only in the AMC but also in Tjietjerkstradeel and Venlo, in Rosas and Murcia. No Van Gogh reproduction, no weeping gypsy girl on black velvet, no ceramic figure turned out by an artistic aunt, but real art.

Maybe I could house some of my growing collection in a doctor’s office in Dordrecht, in a district hospital in Overijssel, with my internist in Barcelona. That way, the patients (myself among them) would have

something to look at, something that not only distracts us but also takes us somewhere. The photo by Paul Kooijker, the painting by Zandvliet and the minimalist sculpture by Karin Sander would be sure to evoke responses. And that way I'd finally be able to break through the silence, even when I'm not there.

15. Discretion

On my desk are two green candies. They're part of a work of art by Felix Gonzales-Torres that consists of a mountain of green candies. Everyone's free to help themselves to the candies, and the owner keeps replenishing them. The work is based on the idea of endless giving. It's an idea that's too expensive for me because the work costs too much money. When I explained that to the gallery owner she told me I could help myself to a few candies. What I wanted to do was to stuff all the candies in my bag and pants pockets, all five thousand, but I realized that would be a bit indiscreet so I only took three. One I gave away, the other two I saved. As usual I now regret my discretion. I don't have the work but I miss it anyway.

Endless giving, the most beautiful idea in the world. Art triggers the finest human impulses and the most horrific. It's just like love. You think the other person was made for you, for you alone. You think the other person would be so unhappy without you and that all you have to do is convince him of this simple truth. You want this other person for your very own, forever. If he's gone, the whole world is empty. Even five billion people aren't enough to make up for that single loss.

Those green candies were meant for me. If they end up with somebody else it's just plain wrong. I can't let them get away with that. But I also can't let myself get away with spending seven hundred fifty thousand dollars for them.

We're in a dilemma, the candies and I. Because I wanted it all I pretended to be discreet. Because I wanted five thousand I only took three. But the candies want to be with me - it's so obvious. Those two on my desk are lonesome. I can tell. They miss the other four thousand nine hundred eighty-nine.

16. Two empty chairs

A photo of two empty beach chairs cut into pieces: a jigsaw puzzle in a plastic bag. It's called *Untitled - Untitled (Last time)*, from 1989.

The puzzle makes me think of my own head - two empty beach chairs cut into pieces, *Untitled*.

Untitled speaks of absence and loss. All that's left are two empty beach chairs. Felix Gonzalez-Torres has used two empty beach chairs to make a work of art. He doesn't say what happened. The strength of the work is that he knows what to leave out so the story can develop. It's the not knowing that seizes me. The puzzle in my head.

Felix Gonzalez-Torres has given shape to what he knows and what he feels. It's a strong shape that keeps on living now that he's no longer here, cut down by the virus that I struggle with every day.

He leaves behind two empty beach chairs.

Maybe it's a photo of his chair and that of his partner, who died two years earlier. Maybe it's a photo of two random empty beach chairs. It doesn't really matter.

Each moment someone else is touched by his jigsaw puzzle story. Felix Gonzalez-Torres lives on. He is an example for me.

17. What day is it today?

"Do you know where we are now, Mr. Nefkens?" he asked.

"In the AMC, doctor."

"And where is the AMC?"

This was a trick question and I was ready for it. If I didn't know where the AMC was it was proof that I was certifiably demented.

"The AMC is in the AMC, doctor."

No argument there. Even so, the doctor was still not completely convinced that I wasn't demented.

"Do you know what day it is?"

I pulled a face as if I couldn't waste my time answering such dumb questions. But I didn't know what day it was. The Christmas decoration on my night table didn't help at all, nor did the calendar for the new year. The snow the doctor pointed to didn't provide any clue as to what season we were in.

The doctor wasn't good at keeping secrets, and at the end of what he called a conversation he told me it was December 31st, that the next day would be New Year's Day, and that the snow outside indicated it was winter. But December 31st, New Year's Day and winter meant nothing to me. No lights went on. Despite the festive season, there were no lights at all flickering for me back then.

December meant nothing, New Year's meant nothing, winter meant nothing. The doctor could have told me it was Turnip, Turnip 31st, that the next day would be the Feast of Carrots and that we were in the season of goldfish. It would have meant all the same to me - nothing.

The next morning he asked me the same questions once again, and once again I couldn't give him a single answer.

It's strange when your own language has become a foreign

tongue to you. It makes you uncomfortable when words lose their meaning. It's also strange to imagine what something is like when you don't know. How do you imagine "nothing"?

Rather empty and bare but restless all the same.

I don't remember how the words came to make sense again. I only know that gradually a number of words recovered their meanings, or acquired meanings that, as far as I could recall, seemed to coincide with what I thought the meaning once had been – the meaning I was supposed to guess at in the hospital.

I recognized nothing but I learned fast. I'm a stranger who's appropriated himself for himself.

I don't even know if this is actually the case. All I know is that this is how I experienced it. What it's like – what it's really like – I just don't know. No one knows what it's really like, but as the years go by you remember all sorts of things, so that it seems as if you know more than you did when you began.

This way you're able to avoid having the impression that all that time has been a total waste. Of course the time has been a total waste, but admitting that would be admitting defeat, so we just pretend. And if we just pretend long enough, we start believing it ourselves.

We believe that December 31st is the day before New Year's and that snow falls in the winter. And because we believe it, we ask other people if they believe it, too. And if they believe it, everything's fine. If they don't believe it, there's something wrong with the other guy. He's someone else we need to feel sorry for, because he doesn't know when New Year's is. He doesn't even know what day it is today.

18. The kindness of friends

The hospital room is full of people. They're sitting in a circle around my bed, doing their very best to keep the conversation going. They ask me how it's going, but it doesn't sound like a question. They already know my answer: stubborn silence.

A roomful of visitors, I think, all of them here for me. I've really got to say something. But what do you say to a roomful of visitors? I ponder this a moment but nothing comes to me. Absolutely nothing.

"It would be so nice if we just knew what was going on inside him," says a worried friend, drawing up her chair so as not to miss any first word I might utter.

"If there's anything going on inside him at all," says another friend.

Bitch. Make sure she doesn't come any more! Because she's got it all figured out. There's nothing going on inside me. And if anything was going on inside me I wouldn't know it, let alone be able to talk about it.

The friends sigh a little. One of them coughs. Another whispers something, very quietly and respectfully as if this were a church, or a museum of modern art.

It occurs to me that I really should say something - to help them, poor souls. But that's all that occurs to me, and I've regained enough of my wits to know that that's the one thing I shouldn't say. So I don't say anything.

"They appear to be aware of their surroundings. That's what you hear about people who've been in a coma for months," says the friend who isn't allowed to come anymore. The others nod. They're not allowed to come anymore either. So it's a good thing I don't say anything. If I were to say anything they'd all be back tomorrow.

"They do appreciate it," says the friend who caused all the

trouble in the first place. One thing I know for sure: if I get better I'm choosing different friends. Friends who don't come to see me when I'm sick. Friends who know there's only one response to silence, and that's to show solidarity by keeping your own mouth shut.

19. Man without a past

I'm a man without a past. Whatever happened the day before yesterday, or eight months ago, or forty-eight years ago: I know that it happened but I don't feel it. It's as if it happened to someone else. Maybe the past will come back, maybe I'm still in a kind of shock. Maybe not. Maybe it'll be this way forever.

It's really no big deal. When I first realized it I thought it was terrible. I'm not the self I used to be. I want my old self back, I shouted. But now I think, what for? I can't do anything about it so I might as well accept it. I'm sharing my past with a stranger. A borrowed past. Every day is new. Everything is new.

(That's not true, of course. There's a lot that's been firmly stamped into me, but I don't know what it is. And ignorance is bliss as far as that's concerned. It's all empty and fresh and tidy. There are lots of strange things I don't understand. But I don't mind; that's just the way it is. I used to want to understand everything, but that's too much for me now. I'm satisfied with a little bit.)

People who've reached the age of forty-eight must have a past. It often weighs heavily on them - I remember that from before. That past can cause all kinds of problems. At least it seems that way to me, if you have a past. But real knowing is something I don't do. Every day is an adventure, everything is new. I used to miss the familiar things of life. Now I'm used to having nothing familiar. And that in itself is something familiar, isn't it?

I'm someone whose life happened to someone else. Except for the now. What's happening now is the only real thing. Some people go into therapy for this or sign up with some Eastern philosopher. I didn't have to do a thing. It just fell into my lap. From one day to the next I lost my past and I was at peace with the present. One cold winter, three icy months, and suddenly it happened.

I just got lucky. I'm a lucky dog. That's me.

20. Virgin

It's damned annoying, all the things that have happened to me in the last year. It's annoying that I'm still dizzy and disoriented, that even after a year I still feel as if I'm about to fall over. It's annoying always to be seasick - seasick when I'm walking down the street, even when the world isn't moving. (Other people think the world isn't moving; they're wrong, of course, but that doesn't make it any less annoying.)

I'm constantly being surprised. That rarely used to happen to me, but now it happens a hundred and fifty times a day. "Is this who I am now?" I ask myself. (I'm not sure I like that). "What's coming next?" I often wonder. (An alarming way to live.)

"What a delicious piece of cake," I think, as I eat my daily serving of Sachertorte at Escriba, the pastry specialist around the corner. Never in my life have I eaten such tasty cake. "That chocolate curl is out of this world," I shout with my mouth full to Christian Escriba, who's known it all along but likes to hear it anyway, every day at ten past four.

Because my memory isn't what it used to be, it seems as if I'm experiencing everything for the first time. And if that's how it seems to be, then that's how it is.

A plate of salad - I wonder how would that taste? Sex - what would that be like? I think they're both wonderful, surprisingly wonderful, especially if they're well made. Fresh lettuce leaves with a bit of oil and vinegar, some salt and pepper, a few pine nuts tossed on top is the most delicious thing on earth. The same goes for sex. There, too, it's a question of genuine ingredients - not too much and not too complicated so the true taste can emerge.

How many people get the chance to experience something twice in their lives for the first time? I do. And it happens to me every day. "What will it be like today," I wonder as I take Ollie out for the same walk I've taken him on every morning for the past five years. And every

morning I'm surprised all over again by the fact that he pulls on the leash. Every morning I enjoy the trees on the Gran Via all over again, and every morning - all over again - I take another deep breath of air.

Every day all over again I luxuriate in my piece of chocolate cake as if I had never tasted anything so delicious in my life; every day all over again I enjoy the colors of Paul Smith and Bernard Frize. I've never been in an airplane before, and I clutch the armrests as we zoom up into the air. "I'm a virgin!" I shout with the chocolate still on my lips as we slice through the clouds. I'll be a virgin forever, every day all over again.

21. Hard to tell

I've been in this seaside restaurant before – one year ago, to be exact. Back then we sat at a table for two; now we've taken our place with many others. There are fifty of us. With most of us it's hard to tell if there's anything wrong, although some are rather quiet.

One man with green eyes hasn't said a single word all afternoon, but when the guy with the accordion comes by he bursts into song. He knows all the tunes and all the lyrics; he sings from his heart and with conviction. Another silent person, a woman, moves down the length of the table and gives each of us a big kiss.

A year and a half ago I didn't belong here. Now I'm one of them, although not the worst example, in my opinion. At least I can talk, but I still remember the days when talking was difficult. The words just didn't come; it was so quiet inside me you could have heard a pin drop.

The things that used to come naturally now require effort. A man cuts the meat for his wife and for all the other people at the table who ask for his help. He can cut my meat, too, while he's at it, if it makes him happy.

It's strange to think about what once was normal and what I can't do anymore, as if something had been taken from us, as if something had been stolen while we weren't looking. If only we had been paying more attention, that man wouldn't have to cut our meat for us now.

In two seconds our whole life changed. And secretly I keep hoping that in two seconds everything will change again, back to the way it used to be. If it can all happen so quickly and so unexpectedly it should be possible to reverse the process just as fast.

It was a bad dream. Open your eyes and everything will be the way it was a year and a half ago, when you didn't even know how ordinary everything was. But when I open my eyes we're still here, all

fifty of us. And with most of us it's still hard to tell if there's anything wrong, although some are rather quiet.

22. Undesirables

You can try hiding them in a supply of empty capsules and then putting the capsules in a vitamin jar. You can put them in little individual plastic bottles and attach a vitamin label to each one. You can buy a suitcase with a secret compartment and conceal them there, but that's a bit more risky. All luggage goes through X-ray machines and secret compartments are discovered in a flash.

I'm not talking about cocaine or heroin but about the medicines that betray my identity as someone infected with the HIV virus. Next week I'm flying to New York, illegally. Anyone who's HIV positive, myself included, cannot enter that country unless they have special permission. And that permission is only given under extraordinary circumstances – to people who are planning to make use of the medical facilities there (at their own expense, of course) or people going to attend a congress. And even then it's difficult to get into the United States. Tourists who are HIV positive are undesirables.

America is one of the many countries we're not allowed to enter. It's pointless to try to explain to the customs agents in Abu Dhabi, Kuala Lumpur, Vientiane or New York that the law is absurd, that the people who know they're infected are precisely the ones who tend to be cautious as a rule, that the symbolic embargo on HIV will not check the advance of the infection in their country.

Some people think up rules and others see it as their job to make sure they're strictly enforced, no matter how futile and inhumane those rules may be. So every time I have to pass through customs in one of those idiotic countries I like to visit so much I break out in a cold sweat. Are they going to open our suitcase? Will they start pawing through the special pouch I use for my medicines and ask me what all those little bottles and boxes are for? And what happens if they don't believe me

when I tell them they're allergy medicine, and they confiscate everything and send me back? I can't skip a single dose because that might create resistance, or it might aggravate any existing resistance, and there just aren't that many alternatives available.

I comfort myself with the thought that if I am sent back I'll be able to take the medicines with me. If not, maybe I can wheedle out a dose or two for on the way.

I always carry a letter from my doctor in case of emergencies. "This is to certify that Mr. Nefkens is suffering from a chronic condition for which he has to take the following medications," followed by a list of six medicines. "Chronic condition" sounds as if it's not contagious or life-threatening so it won't be associated with HIV.

It's a little like the description in the brochure of our hotel in Dublin, "a hotel that prides itself on the elegance, style and warmth of service it can offer visitors." At first glance you think this is referring to an elegant hotel with style and warmth. But that's not what the brochure says; it says that only the service is elegant, stylish and warm. The hotel itself is a dump.

I hope the customs officer who reads this letter will be just as misled as I was by that brochure. But if he wasn't born yesterday and he's got a reference book, or if his computer tells him what kinds of medicines are taken for diseases that he's got to keep out of the country, I've had it. I'll be put on the next outgoing flight and sent to the place of origin.

I'll be sent back - just like all the other illegals, the political and economic refugees, the wetbacks, the boat people, the Cuban *balseros* who don't make it to the coast, the Mexican farm worker traveling without papers, the Pakistani engineer, the Vietnamese mother, the Nigerian university professor who hopes to become a Manhattan taxi driver.

Sometimes I see them standing there at JFK. They're being interrogated and their baggage gets turned inside out. They look embarrassed, nervous, they're gray with fatigue after an exhausting journey. Sometimes they're led away to a special little room where they have to answer more questions, where they're examined even more scrupulously.

What happens to them next is something I never see. Up until now I've always been waved on, welcomed. I have white skin and an expensive leather valise; I don't look suspicious.

I just keep slipping through. I've never even had to show anyone the letter about my "chronic condition."

They think they're doing a good job, the men and women who enforce the rules so strictly. The Pakistani engineer and the Nigerian professor are still sitting in that bare little airport room with the neon light as I order my chocolate soufflé at The Four Seasons. It's the specialty of the house.

23. Joyeux anniversaire

Yesterday was the birthday of my virus. Seventeen years ago yesterday I was given the news that a not very unassuming guest had taken up residence inside me with no immediate plans to leave. I realized this all at once when I found myself sitting before a class of eighty French young people who were just as old as my virus is. I was speaking to them about HIV in the world and HIV in my body. They wanted to know where I had contracted it and how. They wanted to know how I had felt when I heard, whether my life had changed since then, whether there were things I otherwise would not have done. They asked how my family had reacted and they wanted to know if any of my friends didn't want to have anything to do with me anymore after I had told them the news. "My friends aren't like that," I answered in a French that gained in fluency in proportion to the pumping of the adrenaline.

When they'd finished asking their questions I told them I wanted to ask them something. I wanted to know what their reaction would be if they were to find out today that they were HIV positive.

There was a little murmuring, a little giggling, a few stricken faces.

"If I found out today that I was HIV positive I'd rather die right away, because everybody would find that I had done something bad."

I didn't think "bad" was quite the right word. "*Stupide*" seemed better to me. It's stupid to do something that can have serious consequences when the consequences are easy to prevent.

It's much more practical to go through life not doing stupid things, yet we smoke, we eat Big Macs and we run red lights. Sometimes the consequences of such a stupidity are way out of proportion to the act itself. Yet we don't tell someone dying of lung cancer that it was his own fault, and when somebody is killed in a fatal car crash it doesn't make the grief any easier to bear to point out that he hadn't been paying

attention.

There was one thing the group agreed on unanimously: you should show solidarity with people suffering from AIDS. And they didn't say that out of politeness toward me. On the wall of the classroom hung the drawings they had produced after having visited a traveling exhibition of international artists whose work made for the AIDS conference in Bangkok was hanging in the local art centre. The drawing that impressed me the most was based on the photo of hands by Shirin Neshat. One of the students had written "*solidarité*" around the edges of the hands.

All the students thought you should show solidarity, but they were also afraid of how other people would react. Maybe it would help if there was more talking on the subject, I suggested, but they didn't regard talking as a very interesting option. The students wanted a condom vending machine in the recreation room *and* they wanted to do something for people with HIV.

I told them about Mercy Centre in Bangkok where people with AIDS are cared for, and about the possibility of adopting a child with HIV. For 2000 dollars a year that child will receive care and medication.

The students immediately swung into action. They thought of ways to raise money and decided there should be a bulletin board in the recreation room with news about the child adopted by the school – not too big, of course, because there had to be enough room for the condom machine.

So that's how the virus and I celebrated our birthday: with the students of Altkirch in honor of little Note in Bangkok. The words of "Happy Birthday" rang out in France and could be heard all the way to Thailand.

24. A fellow passenger

The Boeing 747 taxis down the runway at Mexico City airport. I ought to be glad I don't live here anymore. The suffocating air pollution, the impossible traffic and the increasing violence make the city uninhabitable. But no matter how often I point this out to myself, I'm not happy. It's true: everything that can go wrong with a city has gone wrong here. It's chaos, nothing works and the corruption strangles every attempt to improve conditions. Yet these are my people; it's here that I feel at home.

Since finding out I'm HIV positive I can no longer live in Mexico. I can't get the combination of medicines here that I need. The medical services here can't be compared with those in Western Europe. I have no choice. I have to leave.

As the plane lifts off I swallow hard. It must have something to do with the changing air pressure in the cabin. The Mexican women next to me swallows, too. She brushes her eyes with the back of her hand and turns to gaze out the little window.

I think about what I've lost. Because of that stupid virus I have to leave Pedro, and Juan and Silvia. And Jorge, who I always laughed with about the nicknames we gave everyone. No more latest news from the neighborhood, no more watching the neighbor lady in her pink duster watering the geraniums on the balcony. I'll miss the rolls from the baker on the corner, so fresh I could feel their warmth through the paper bag as I carried them home.

There'll be regular phone contact, of course, and Silva and Jorge will keep me posted by e-mail. Europe has neighbor ladies in pink dusters - and warm bread. But it's not my neighbor lady. The rolls aren't from my baker. The warmth feels different. No matter how long I live outside Mexico, Avenida Mazatlan will always be my street.

I shut my eyes and dream about the country that feels like it's mine and about that other country - the country I come from but that's always been alien to me. I belong here in this blue aluminum tube between two continents, and I just want to keep flying.

When we land at Schiphol eleven hours later I smile at the woman next to me, who spent the entire flight looking outside, even when there was nothing to see but the night sky. As I stand up I say *hasta luego* to her, good-bye.

"Hasta luegito," she answers softly. She uses the diminutive, just as my neighbor lady in the pink duster always does, as if reducing reality could mitigate it somehow. I miss that, too - the reality that must be disguised, the truth that must be softened.

At Schiphol they wave me through. I don't even have to open my passport. I look Western; nothing suspicious about me.

I turn around and see my fellow passenger being led away by two customs officials. She looks so small and fragile between those two Dutch trees. I'm tempted to walk after her, to ask if I can be of any assistance; perhaps I can translate. But my Dutch friends are waiting for me in the arrivals hall. I quicken my pace. I have things to do.

25. Undetectable

Blood tests from 8:30 to 9:00 a.m. Please be prompt.

The message is written in Catalan and, in somewhat smaller type, in Spanish. It's well before eight-thirty and a line has already formed in front of the still locked door. The sooner you arrive the sooner you can leave.

Manuel is at the very head of the line. We know each other from years in the waiting room. Behind him is a girl not yet twenty, two men our age, a somewhat older gentleman and a lady wearing a gray suit and a string of pearls. How can a lady in a gray suit and a string of pearls be infected with HIV? Impossible! Surely her pearls would have protected her from such a vulgar virus.

Ever since the introduction of potent cocktails about five years ago we no longer see gaunt specters come rolling in in wheelchairs. The emaciated patients with Kaposi Sarcoma wounds on their faces and arms, the "victims" you used to see so often in documentaries accompanied by somber cello music, are no longer in evidence here.

We look pretty healthy. For many of us the amount of virus in the blood has dropped so far that it can't even be detected with advanced equipment. The virus has become undetectable.

Five years ago they were still having conversations here about the fellow waiting-room habitués who hadn't made it.

"Did you hear about Pedro?"

That sentence alone was enough to tell you that you wouldn't be seeing Pedro in the waiting room any more. With each routine visit we'd be down by one more of the ten little Indians, although the waiting room would be none the emptier for it.

Almost no one dies of the virus these days. In the First World

it's simply not done to die of HIV in the twenty-first century. No more sick calls are arranged, the buddies are unemployed, the support groups have fizzled out and the books by Elisabeth Kübler-Ross on healthy dying have all been sent up the chimney.

Now we exchange addresses of masseurs who massage away the lumps, of acupuncturists who prick away accumulations of fat, of herbalists with brews for nausea, of beauty specialists who apply creams for collapsed cheeks.

The doctor's visit every three months, the blood tests - it's all become routine. It doesn't mean anything any more. Well, almost nothing. Except when something suddenly goes wrong, when the medicines turn out not to be strong enough, despite all the side effects, and the virus stubbornly raises its ugly head once again. Then we decide it might not be a bad idea to push up the date for that trip to New York we had planned for the summer. We call the friend we hadn't spoken to in six months, and buy roses for our beloved. When something suddenly goes wrong, the ghost of Mrs. Kübler-Ross, with her windswept permanent wave, starting peeking at us from the around the corner. The horizon shifts once more.

We comfort ourselves with the thought that the horizon has shifted so many times in the past years - closer, farther, back again - that it's no wonder we feel seasick every now and then. The viral cargo rose and dropped and rose again, but we're still here. As in the American TV series, where the poor slob who's hanging out the window gets pulled in just in the nick of time by the hero with the beefy arms, there's always a last-minute rescue for us in the form of a new medicine. The strong medicine doesn't pull us all the way in, but it holds onto us so firmly that we no longer have the feeling we're half dangling from a window ledge.

"How's it going, Manuel?"

"I'm undetectable. How about you?"

“Me, too. Four hundred seventy T4s.”

“I’m three hundred twenty. The doctor said it’s a little low because of the Hydrea, so actually I have plenty more T4s.”

“As long as we stay undetectable nothing can happen to us.”

“Whatever you say. Looks like it’s my turn. See you in three months.”

“In three months. And take it easy now.”

26. Collage

Five past four. In the morning, I think. Barcelona, I think. In the distance I can hear the wail of police car sirens echoing among the skyscrapers – way in the distance, where it’s now five past ten at night.

Got to get some sleep. *Got* to get some sleep!

Tomorrow I have to get up early and write a piece about New York. Got to hurry up or the images will just evaporate. Some of them haven’t even survived the journey; they’re stuck somewhere between Newfoundland and the Irish coast. The rest is one big incoherent collage in my head.

The gleam of the waxed and polished blond wood floor of the Nicole Fahri shop is heightened by the dozens of spotlights aimed at Julia Roberts and Hugh Grant. A movie is being made in the shop’s restaurant.

Hidden behind the racks of black and brown leather jackets, I watch Hugh offer Julia a light. “Cut! Action! Cut! Action! Cut!” Thirty-three times the same fumbling gesture, thirty-three repeats times the same disarming smile.

Whenever we hear the cry for “action,” the two other customers and myself have been instructed to keep our mouths shut – as if we were able to utter anything at all, star-struck as we are. Back home I discover I’ve bought four leather jackets. And as for the twelve shirts that are also in the bag, I don’t remember a blessed thing.

An enormous billboard right off Union Square features an attractive blond man, laughing.

“I’m positive,” it says. It’s an ad for the anti-HIV medicine Zerit. So in America we’re not just pathetic examples of humanity; we’re ordinary consumers. It’s an ad like any other – for shampoo, or socks,

or a bank loan. Zerit won't work for me any more, but the fact that there's an ad for it right on the street moves me to such a degree that I want to kiss the young man in the light blue sweater right on his paper mouth. Can't get close enough, unfortunately.

But I can't think about all this now. I've got to sleep. Close your eyes. Don't concentrate on anything.

Did I actually pay for those Nicole Fahri jackets? And the twelve shirts?

It was such a mess, dozens of people from the film company walking around and the salespeople loitering right next to the cameras in the hope of snagging a role as extras. Should I get in touch with the shop? Should I give them my credit card number over the phone? Or should I just let it go? I've bought so much from Nicole Fahri already that one small courtesy is certainly in order.

A refined, off-white business card is what I get from the lady in blue silk, the one I've been speaking with about architectural photos during the fundraiser for a Brooklyn musical group. "Barbara Field, philanthropist and collector" it says in silver letters. How can you not love a country where you can be whoever you want?

Everything's for sale here – a fridge with built-in peanut butter machine, a new nose, immediate enlightenment and spiritual insight, a spanking new identity. A new identity – I've been looking for that for years. Would it fit in my suitcase, or should I pack it in my carry-on to be on the safe side?

An Italian restaurant in Soho.

"How many people for lunch?" asks the Polish waiter.

"One people," says the Venezuelan gentleman.

"O.K. One people for lunch."

Breakfast spot in the West Village. Mexican family of four.

"Is possible fried eggs?"

"Fried eggs possible," answers the waiter from Bulgaria.

Prince Charles was absolutely right when he called Badly Spoken English the international language.

Chelsea. Gagosian Gallery. Damien Hirst. I open the door and I'm greeted by a giant anatomical model at least five times bigger than I am.

Damien Hirst, the artist who exhibited a tiger shark in a tank of formaldehyde solution, is not a man for understatement, so New York suits him to a T. Blue and yellow tropical fish swim in an aquarium with a gynecological examination stool at the bottom. The wristwatch, the chain of pearls and the rings belonging to the patient are lying on a somewhat rusty little steel table. Next to the table are her bag and shoes, sensible clodhoppers. The madam herself has dissolved in the water, and so has her doctor.

Perhaps a dash of formaldehyde might have saved them from vanishing, too.

In a steel mirror-faced cabinet, Hirst has eight thousand pills on display. The beauty lies in the rhythm of repetition, the extra dimension provided by the reflected image, the alternating colors, the splendor of reality stretched all out of proportion.

Standing there, I calculate how many pills I keep in my yearly cabinet: nine thousand four hundred ninety. The cabinet for the past thirteen years would contain a cool hundred twenty thousand pills.

There's nothing out of proportion about this. It's reality. But lots of reality all at once gives the impression of overkill.

Outside the Gagosian Gallery an enormous limousine pulls up. The chauffeur opens the door for a small, dark woman in black pants,

black turtleneck and beige Prada jacket. A gentleman in a dark suit follows her. From the self-confident manner with which the woman enters the gallery it's clear that the gentleman belongs to her and not the other way around. Is she a collector and therefore important, or is she important and a collector to boot? She's somebody in any case, because she's stepping out of a stretch limo. You can measure a person's importance by the length of the limousine. On the way to the subway a gentle rain starts to fall.

Five thirty. Still haven't shut my eyes. I'll never get any writing done tomorrow, I know that now.

27. On one leg

He was about eight or nine. He could have been twelve, too. (It's hard to tell with Thai children.) Petch pulled me into the middle of the classroom where the children have drawing and singing lessons and proceeded to stand on one leg. I couldn't understand a word he said, but I caught onto this right away. It was a trick I sometimes do myself: try to stand on one leg to see if I can keep my balance. I've been doing pretty well recently but sometimes I fall flat on my face, and I always wish I had a hand to hold whenever I try it again. I felt Petch's fingers squeezing around my wrist, and when he almost fell he came close to pulling me down with him. Monti, the artist who gives drawing lessons to these HIV-infected children in the industrial town outside Bangkok, told me Petch's story. Last year Petch had been very sick. The virus had affected his brain and he could no longer walk. Now things are really looking up and last week he showed her, with enormous pride, how he could stand on one leg. Almost. Petch started tottering once more and I threw my arm around him, not only to keep him upright but mainly to acknowledge the fact that Petch and I are a lot alike. I told him through Monti that the virus had affected my brain, too, and I had been very sick, but now I was back to my old self and I could stand on one leg as long as I wanted. I gave him a demonstration, started wobbling and grabbed onto Petch at the last minute. But I gave my wobble a quick twist to make it look as if I were executing an ingenious dance step. Petch saw through me right away and had a good laugh. Only comrades in arms really understand each other.

I wanted to give him a pat on the head but remembered just in time that the head is a sacred place for Buddhists and under no circumstances must you touch it, so I gave Petch a pinch on the shoulder. He smiled back broadly.

A little while later Monti asked if I wanted to say anything to the children, and I told them that even though we come from very different worlds we have a great deal in common. I don't know how Monti translated it but I doubt the children understood what I was talking about. At first glance a middle-aged *farang* glowing with health doesn't appear to have a lot in common with Thai children, whose bodies are so gaunt and little faces so pale. Perhaps I was the only one at that moment who was convinced that there was hardly any difference between them and me.

I quickly pulled out the plastic bag from *El Corte Ingles* and began to hand out candy bars and Bounties, so my little Thai friends would finally get something that was worthwhile.

28. Scapegoat

I'm more than happy to blame it on aphasia. It's such a handy scapegoat for everything that goes even the least bit wrong these days. A little confused, a little bewildered, a bit stupid, all in a tizzy? It's that wretched disease, that business in my brain. I really can't help it.

I even blame it for the nausea I've been having for a year now: "Aphasia, you know." But I had that nausea before the aphasia hit me. Nausea is a well-known side effect of the anti-HIV medicines I'm taking, all five of them. Side effects have long been out of fashion, though, and you never hear me talking about HIV any more. So many people have it; it's so common. But aphasia - that's a much more complicated name. Few people have heard of it; it's far more exclusive. I'd much rather have that.

I have both, though, which is something I'd occasionally like to forget. That's a symptom of aphasia, forgetting. You forget a lot, and like a good aphasiac I'd really like to forget that common complaint of mine. But the nausea doesn't go away. I have it all the time, although sometimes I'm less aware of it. It has to do with getting used to it, and with the aphasia. Every cloud has a silver lining, they say. But in the evening, at about eight o'clock, things start going wrong. I'm hopeless. I'm sick and tired and all I want to do is go to bed.

I haven't had an appetite for ages. If I do get hungry it's over after a couple of bites. I can still remember when I could eat like a man possessed. There was never enough. I could go on forever. A cow, a calf, half a horse - and I still couldn't sleep for the hunger.

Those days are gone. I dread meals now. I never feel like eating anything, except the things I never liked before. Candy, for instance. I never get hungry but I could easily work my way through a piece of Sachertorte - as long as it comes from Escriba. Because I'm never really hungry any more I've become terribly critical. It's got to be the

very best or I won't eat it. That's sort of an excuse. I look for excuses for not eating, the opposite from how it used to be.

But I can't really remember what it was like back then. Fortunately that's a symptom of the aphasia and not of the HIV. I think. I tend to mix up the symptoms with the side effects.

As I already said, I'm a little mixed up. And that's another part of the silver lining. Because I'm a little mixed up these days I happily blame it on the aphasia. It's a handy scapegoat for everything that goes even the least bit wrong. Or did I already say that?

29. Practice

This has gone on long enough, I said to myself. Fifteen months is too long for a nightmare. There comes a point when you can't take it anymore. I went to Asia to burn it all away, but it didn't work. My nightmare didn't go up in smoke, and I spent most of my time in the john.

So I came back home, seething. Asia doesn't work anymore. Asia doesn't do it for me anymore. We've got to come up with another strategy.

At first I wanted to burn myself away, which would have taken care of the problem once and for all. But F. pointed out what a terrible mess that would make. F. is such a party-pooper.

So I decided to do something else. I decided to take up sports once more, to build up my muscles, to get strong so nothing will ever happen to me again. Yesterday morning I had my first power sport lesson with a trainer who's also a physiotherapist. This was F.'s idea, which once again proves how hopeless he is.

The physiotherapist listened to my story and proposed that we start slowly with a few walking exercises. That ought to fill up our sixty-euro hour in no time, I thought, and proceeded to fall down. Very good, now let's do it again. I had to walk upright without looking at the ground. I had to walk upright without falling. And that I couldn't do.

"I don't want to walk upright," I screamed at the physiotherapist. "I want muscles. I want to be strong. I don't want anything to happen to me ever again."

"That sounds like a good idea," said the physiotherapist. "Let's try walking once more. Just hold on to me."

We had another try. I tottered and reeled. I almost fell down but was able to catch myself just in time by grabbing the shoulder of

the physiotherapist. I tried it again without holding on and landed flat on my face.

I'm forty-eight years old and I have to learn to walk again. I'm not convinced it's such a great idea, but I don't see any alternative.

You've got to keep on going. They never ask you if you feel like it. They never ask you what you'd rather do. Life is no Singapore Airlines - fish or chicken or vegetarian. You've just got to keep on going. Life is a conveyor belt that never stops. Until it stops for good, but that's not good, either.

Today I'm going to do my exercises at home - one leg up and the other leg down. Or something like that. Fortunately my physiotherapist has written it all down or I'd forget it for sure. Because walking is a pretty complicated business. It's something you've got to learn, step by step. I'm going again tomorrow.

30. Highly recommended

Just as eskimos have a hundred words for snow, my mother had dozens of ways to describe how tired she was: I'm done in, I'm bushed, I'm worn out, I've run out of steam, I'm too pooped to pop, I'm all tuckered out, I'm dead on my feet, and mainly I'm all in.

Now that the new combination of medicines leaves me tired so often, I find myself repeating those expressions every day. Each time I say I'm bushed, pooped and tuckered out, I think of her. This is what she must have felt like. Only now do I really understand. The fatigue is a connection through time. We've become allies, my mother and I. But it's an alliance with an emotional charge; I don't want to be as she was - so quiet, so exhausted, so withdrawn - and then, at the age I've reached now, so inexorably gone. Maybe that's why I resist my own tiredness, a resistance that requires energy - the very energy I have so little of.

So I keep on pushing myself: just ten more minutes on the steps machine, half an hour more writing, one more phone call, one more e-mail. And I do it, too: I work off sixteen more calories, write one more paragraph, call a friend in Mexico, answer the gallery owner in Iceland, just the way my mother would take just one more walk with my brother to feed the ducks in the park, or take me to town to buy new shoes. Like her, I end up in bed an hour later with nausea and a throbbing headache.

Fatigue is intangible. It's not a broken bone, not a wound on your arm. You can't see it, you can't touch it. It's not an ache you can feel. It's not even sadness. It's the complete absence of something, the absence of energy. There's so little left over. Without that vitality I feel vulnerable and insignificant. Weak.

But my lack of strength forces me to make choices. I can only expend energy on what's really important. The rest gets thrown

overboard. Contacts that I maintained out of courtesy have been dropped. Tasks that I used to gladly take on I now try to delegate. To my surprise and (admittedly) slight disappointment, I find that other people can do these things just as well as I did, if not better. Shopping for hours is out of the question now. I've got to get it all done in one or two shops. I can no longer allow myself to dilly-dally when I make decisions; I've got to trust my first impulse. And having doubts about what's already done is a waste of energy that I can no longer afford.

What was never achieved after years of therapy has now taken place, thanks to a potent combination of HIV inhibitors. Kaletra, abacavir andamprenavir. I recommend them highly to anyone interested in living a more streamlined life. There's no cocktail more effective.

31. Bargaining

I'm spoiled. Spoiled rotten. As is befitting of spoiled people, I regard it as a good thing when my opinion is taken as the generally accepted truth. The only time you hear anything from me is when things don't go my way. Then I grumble about problems with aching muscles and a strange tingling in my feet. I complain about diarrhea and nausea, and whine about the weird dreams that repeat themselves every night like films I've seen ad nauseum. I curse whenever I look in the mirror and discover a hump on my back and a constantly growing roll of fat under my chin, while my arms and legs are getting skinnier by the month. I tug on my expanding belly and wonder whether going to the sports school five times a week is really worth it.

But everything is fine - more than fine, because I just received the results of my blood test. The numbers that ought to be high are high, those that ought to be low are low. For more than three years now everything's been lovely, hardly a virus to be found in my blood, and my T4s are two times higher than when I didn't have a belly or a double chin.

I think back for a moment to eighteen years ago. If I could have cast a glance back then on the paper that I'm holding in my hands now, even if only for a fraction of a second, I would have slept much better. Back then all I could do was fantasize that everything would have a Hollywood ending. I know perfectly well that those films have nothing to do with reality but they still bring a tear to my eye. I bargained with an entity whom I am almost certain does not exist. It was a bargain between unequals, a six-year-old boy and a parent whom he knows will have the last word in the end. I speculated on receiving compassion from someone whose existence I denied. I tried my best to camouflage my greediness. I asked for five more years, year after year, and hoped that the stern father wouldn't catch on to the fact that I had cheated.

I especially didn't want to come across as impudent, because children who ask for things get skipped over. And so I pulled my own leg and the leg of the non-existent Other.

Slipping the paper with my blood test results back in the envelope, I think about Jorge and Pablo and Kees, who did just as much hoping and fantasizing and leg-pulling as I did. They became bargaining super-stars. Except in their case it didn't work.

And I think of my far too skinny but cheerful little friend Note, in Bangkok. He's eleven years old but he looks like seven. During my last visit he grabbed my hand and took me to the classroom where his latest drawing was hanging: blue sky, dazzling sun, laughing orange fish in the sea that he has never seen in his life.

But when I looked in his medical file I turned pale. The virus is tearing through his blood. His T4s can be counted on the fingers of two hands. His skin infection is now more or less under control and he's survived a bout of pneumonia, but whether he could stand another bout is highly doubtful. Yet he wants to live as much as the rest of us.

I stick the envelope in my archive, which is already beginning to bulge a bit. Soon I'll have to get a new file folder. And most likely another one after that. I might as well buy a dozen right now; it's cheaper.

Otherwise I never think about anything. Normal is normal, and you won't hear me talking about normal. So I make my little dance in secret, in the bathroom, with the door firmly locked.

32. Theater

I'm not going to the theater anymore. I spend hours every week in the waiting room of the Aphasia Society, and no performance can beat that. It's a feast for the eyes and it doesn't cost me a thing. Well, that's not entirely true. It's cost a lot. A whole lot.

Yesterday I was there for an hour, between my lesson to learn to read again and my lesson to learn how to ventilate my feelings. A woman told us about her husband, who can't talk any more. Two months ago he had a stroke. She said he gets angry when she doesn't understand him. He starts shouting all sorts of things, clasps his arms around his body and moves his head wildly up and down. It shocks her and she doesn't think it's fair. She does everything to help her husband and all he does is get angry at her.

David cracked up his car thirteen years ago. Since then he hasn't been able to do anything. After thirteen years of exercising three times a week he can walk a little and talk a little. But when he can't find the right words he gets angry. Extremely angry.

I'm going to the waiting room of the Aphasia Society, the only place I know where the people are angrier than I am.

Jose Luis has been coming to the Society for five years. Things are going well with him now. Five years ago he could neither walk nor talk. Now he can move around and make noises. A word to the wise (even a mixed up word) is sufficient. He says vacuum cleaner when we all know he means speech therapist. We're all wise here in the waiting room.

Mr. Pereira can hardly talk, but he can sing beautifully. He doesn't know any words but he knows the lyrics to all the songs.

I imagine making some kind of contact with him by means of a small operetta, but my voice isn't as good as his.

"What's your granddaughter's name, Mr. Pereira?"

“No idea.”

“How big is she?”

He points to his waist.

“Two months.”

“That’s impossible.”

“But it’s true.”

“Is she two years old, perhaps?”

Mr. Pereira nods and looks around happily, with those big green eyes of his that always seem as if they were about to disappear into his own face.

Participatory theater. I’m audience and actor at the same time. The only problem is that I’m not entirely sure when I’m one and when I’m the other. Do other people see me this way, too? As I write this, is there someone in Barcelona who’s writing a piece about that strange crackpot he saw in the waiting room of the Aphasia Society? The person who doesn’t say much but makes up for it by looking around all the time? Actually, I don’t care if some other maniac is knocking out something at the keyboard of his computer. It’s proof that I belong there, that my place is in the waiting room of the Aphasia Society, four times a week. And it doesn’t cost me a thing. Not a thing.

33. Mechelen chicken

After they’re gone from this earth, people continue to live on in the minds of others as a color, a shape or a gesture. Only one aspect remains, and sometimes it’s not the aspect that they themselves would have chosen. You can’t decide how you’re going to live on in the minds of others.

Part of my memory has fallen into deep sleep. Two weeks ago I was walking around an exhibition in Amsterdam. I was bombarded by thousands of images, but now all I see is the head of a Mechelen chicken and people in a truck with plastic pulled over it. How does my head work, anyway? Why do I see those two images and not the nine hundred eighty-nine others? How do I make my selection? Why do I select in this way and other people select in another way? Why this and not that - that’s the question of life.

The people I know, the dead ones and the living ones, are works of art. They live on as colors, a shapes, gestures. They’re wearing their nicest clothes, but I only see a button, the edge of a sock, the crease in a pair of pants. The detail has become the whole for me, and I break down the whole into pieces so I can take them for my own.

I only have a piece of the world, and for me that piece is everything.

34. Two lives

I'm an old-fashioned HIV positive guy. I go back to the time when all you had was AZT, which you had to take every four hours, even in the middle of the night. I'm from the time that the HIV positive support group was constantly overhauling its membership roster. People kept dropping off, to be replaced by new ones.

In order to figure out whether it's outside events that change you, or whether you always undergo a kind of development in the same way, you'd have to live parallel lives – one life where everything is happening and a second, protected life that would function as a control group.

Back then, in 1987, I decided that the virus was not going to get the better of me and that I was going to live every minute to the full. I wasn't the only one to make such a decision. But many people never had the chance to stick to that resolution.

I stopped smoking, I didn't drink another drop of alcohol and I quit my job as a radio correspondent in Mexico and Central America, working for VARA and various American radio stations. The irregular life of the journalist, which includes burning the midnight oil, was not good for my health. Thanks to the financial support provided by my father I was able to devote myself to what was really important to me: writing. My Mexican friend and I left Mexico City and went to America, where the air was fresh, you could walk down the street in broad daylight without suddenly feeling a gun being put to your head, and where I could get better medical care. In four years we had moved six times, and finally we decided to divide our time between London, Bangkok and Barcelona.

In 1995 my debut novel *Blood Brothers* came out. It was the story of two brothers, both homosexual, both HIV positive, and one of them dies of AIDS.

It was about things that had been left unsaid, about the reality that never gets talked about. Maybe that's the motivating force of my life – talking about what I really see, searching for secrets and revealing them. I'm nothing but an exhibitionist and a tattle-tale.

In 1987 I started living every minute of my life as if it were my last, except there were an awful lot of last minutes. The intensity of the moment began to wane after fourteen years, especially when the cocktails of HIV inhibitors were discovered and my viral charge became practically undetectable. But life is wise. Just when I started taking it all for granted I came down with encephalitis, and once again it looked as if I wasn't going to make it. I was given a second chance at death, but I did not avail myself of the opportunity. I'm not in the habit of dying.

It was quite a time – learning to talk and eat and walk again, learning to write again. And sometimes it was annoying to have forgotten so much. But the opportunity to start all over again at the age of forty-eight is granted to only a few. I can't complain, although I still do at the drop of a hat.

I used to divide my life into the period before I knew I was HIV positive and the period afterward, when life really began. Now I divide it into the period before and after the encephalitis. After 1918, when people talked about “the war” they meant World War I. After 1945 they meant World War II. I just hope that a long stretch of peace has broken out.

35. Birthday

Victor would be forty-five years old today. What would he look like at forty-five? It's hard for me to imagine him as a middle-aged man. For me he'll always be a boy of thirty-one, a lost boy, a boy I lost.

I'm not a very sentimental sort of person. There were years that I didn't even remember his birthday. But this morning I suddenly felt an enormous need to speak to him, to tell him for the zillionth time how I can still remember exactly what it was like the day he was born. I was staying with our grandparents in The Hague and I was playing outside in my new short sleeved shirt, it was a beautiful summer day. I was playing on my scooter when my youngest aunt, who became his godmother, walked up to me. She was wearing a white dress with big red flowers printed on it, and her gold charm bracelet jingled as she grabbed the handle bars of my scooter and congratulated me on the birth of my second little brother. I still remember being so happy that I started riding my scooter as fast as I could, over the sidewalk, around the corner, down the street and back again. He knew the story backwards and forwards but I always wanted to tell it to him again. Then he could act as if he were hearing it for the first time, just to please me (and to please himself, too).

I can't congratulate him any more, of course. Anyone who doesn't make it get a flower on his grave, tops. But I'm not big on visiting cemeteries. Tombstones leave me cold.

The ferocity of my feelings surprises me – even now, after thirteen years. But it's not even now, it's suddenly now.

In the last three and a half years I've used Victor's death as a test to see whether my feelings about the past have really disappeared. I would think about it and wait to see what came to the surface. Nothing. I could still clearly remember the moment in the hospital at three o'clock in the morning, the closed eyes that had just been looking up at

me imploringly, the hand already growing cold. But I felt nothing. No sadness, no outrage, no longing. "It's gone," I thought with satisfaction. "The past is erased forever."

I could still remember it all, but it was as if I had heard it through the grapevine – like the Dispute of the Hooks and the Cods, a historic event that you know once took place but that has no other meaning for you.

I used to repeat the test on a regular basis, and to my great relief I found that it was still gone. Having an empty hard disk like that was inconvenient, too. Sometimes it was extremely impractical. But that was the price I had to pay for the freedom of a now that was no longer stuck between the past and the future.

Last year I started worrying again about little things – a jacket that I probably shouldn't have bought, a bit of writing that was long overdue, an account of something that could have been more nuanced. I became anxious about nothing. I began to be my old self again. I didn't accept it in its full intensity and hoped it would just go away. But it didn't go away. My tears this morning were for Victor, whom I missed, and because the anesthetic turned out to have been only temporary. I cried because I've recovered. At least, I have.

36. Fahrenheit

The astonished English serving girl working in the cafeteria at the zoo, where I was sitting with Vincent at a sidewalk café, cried out the name of the aftershave I was wearing. We had to laugh, my brother and I. We imitated her accent and said “Fahrenheit” to each other the way she did. My brother liked the fragrance, too. He didn’t pay compliments very often, which meant that Fahrenheit was special.

Vincent loved zoos. We saw a lot there together, he and I.

A few times I’ve been at the point of changing aftershaves, but then decided not to. He knows what Fahrenheit smells like and I don’t know what he thinks of the other fragrances. He doesn’t know any of the fragrances that have been put on the market since ’92, of course, but with Fahrenheit he can always find me. It’s been a long time since I could smell it on myself, which means other people can smell it on me all the more. When you stop smelling something you no longer know how much you’re putting on. And that’s my problem. Knowing how much to put on.

This morning I changed aftershaves for the first time in eleven and a half years. Starting today I’m not using Fahrenheit any more but Acqua de Gio by Armani. It’s a betrayal, posthumous disloyalty.

I bought the bottle of new aftershave a long time ago. For months I hesitated. But this morning I threw the half-full bottle of Fahrenheit in the wastebasket and opened the new one. I only used a few drops, making sure it wasn’t too much. I have to get used to it.

Does this change in fragrance mean I’m admitting to myself that he will never find me again? Does it mean I’m giving up hope? Or does it mean that life is over? For good? Is it a victory or a defeat? I don’t know. I only know that I smell myself now for the first time in eleven and a half years.

I no longer smell familiar. I smell like now. But maybe he’ll find

me anyway, despite the different fragrance. With that thought in mind I took the plunge. I keep finding new ways of fooling myself. One lie is more ingenious than the next. The most ingenious lies are the ones I haven’t thought of yet. The lies that show the truth as trickery, are still beyond me.

Maybe he’ll recognize me some other way. Maybe he’ll recognize me by the way I think instead of the way I smell. Maybe he’ll recognize me by the way I think about him - still.

If he looks hard enough he’ll find me. But I don’t know if they spend a lot of time searching, there where he is now. They probably don’t search at all, because they have everything that their non-existent hearts desire.

Searching is something we do in this life. I don’t know what happens after that. I really don’t know.

37. This bird has flown

Three and a half years ago, ignorance was liberation. It was annoying not being able to read or do simple arithmetic, or to understanding anything about the films and TV I watched. But the aftermath of my encephalitis kept my life light and tidy. Only the present moment was real. The only demand I made on myself was to learn to walk again without falling over. Now I walk without thinking about it, as straight as I did before and even a bit more resolutely. I'm reading again, and writing and making plans and organizing things. Yet I don't feel like my old self because I can't remember what that old self was like. I don't want to know, either. I cherish the illusion that everything I had been taught is gone for good, like a computer virus permanently erasing parts of a hard disk. Years of acquired twists and turns in my brain are gone. Only the core remains.

That ignorance wasn't always practical. You're expected to be aware of certain things in this life, but I found it rather pleasant to travel without luggage. I had the feeling that I was making more headway without having to schlep that trunk full of old garbage around. Living in the now is the ultimate freedom.

But in the past few months I've noticed that I'm actually getting better. The future is starting to force itself upon me, and it keeps casting its shadow over the present moment. No matter how sunny I try to imagine my future, every minute I'm there is a minute stolen from the now, and that's a damned shame. On top of that, I don't always imagine my future to be an entirely cloud-free proposition. I regularly catch myself getting anxious about a passport that may not be ready before I go on a trip, a piece I still have to write, a speech I still have to prepare.

Three and a half years ago I longed to go back to the year before, when I still knew everything and could do everything. Now I

want some of that innocence back, the innocence I had when I didn't know anything at all. I yearn for my own virginity, even though the first wedding night is long over.

Wanting to hold onto everything is exactly what used to make my life so heavy, and once again I'm catching myself wanting to lay my hands not only on what's already there but on what's not there yet. I want to feel the future. I want to possess it now.

That desire always to want to hold onto things is turning my head into a tiny cell. There's no prison more oppressive than the one you build for yourself. Now that I'm back on my own two feet, I gaze wistfully at the bird flying overhead – the bird I used to be.

38. Africa

I had been a long time since I'd seen them on television and in the doctor's waiting room: the emaciated bodies. But last Wednesday, World Aids Day, there they were again. Not *again* – still. They've never gone away. I just hadn't seen them in a while.

I can learn to live with a lot of things: my own impulsiveness, the drizzly rain in Holland, the old men in the Raval who spit on the sidewalk. But these are images I can't live with. And they can't either.

In my kitchen cabinet there are five bottles of medicine, medicine that could make the people in Africa just as strong and glowing with health as I am. So doesn't Federal Express go to that continent? Why me and not them?

I've thought about it for the past three days and I haven't come up with an answer.

"Me and not them" is bare and cold and lonely, for them and for me.

There isn't much to be done about my impatience. The rain in Holland is not something I can do anything about, no matter how much I'd like to. And just now I almost slipped on the phlegm left by one of the old men. But how about a multiplication of the medicine bottles in my kitchen cabinet? This sort of thing already happened once before, if I'm not mistaken. Unlike the event that took place two thousand years ago, however, this one doesn't have to be a miracle. I'm sure we can find a way to get my medicine bottles into the kitchen cabinets of Africa.

Next year I'd like to see less of that on television. I'd like to see less without having to shut my eyes.

39. Bursting heart

Why doesn't my keyboard overflow when my heart is bursting? There's so much to write about. The images of two weeks ago, when I went to the beach in Thailand to paint with thirty-five little Thai colleagues and forty attendants, are still fresh in my mind.

Even though I'm now seven thousand kilometers away, I can still see the bulldog pin in Muk's pitch black hair as plain as day. The heels of her plastic shoes, sparkling with pink glitter, are so high that she can barely walk in them.

I can hear the excited shouts of Jeeranak as he catches a glimpse of the sea for the first time in his life. He runs up to the water's edge but is stunned when the water splashes against his legs. Recoiling for just a moment, he takes a running jump and dives into the waves, clothes and all.

Two little friends spend the whole day doing nothing but whizzing up and down in the elevator of the enormous atrium lobby of the hotel. They wave to me and I wave back. At each floor they grow smaller until I cannot see them at all.

Dangling from the neck of the little girl with the bead rings is a name plate written in those decorative Thai letters that I can't read. Only later do I learn that my plate says "Doctor Han." This patient has to go all the way to Thailand just to be a doctor for a few days.

In their turn, the children cannot read the English texts written on their T-shirts from the street market. "Marihuana girl - she traded her body for drugs and a good time" is emblazoned across the bosom of an eight-year-old girl. "I called in sick so many times, next time I'll call in DEAD" announces the green T-shirt worn by Muk, whose arms still bear the marks of a recent skin infection. Every time our eyes meet she laughs at me in that typical Thai way - shy and captivating at the same time.

The T-shirts we're all given - white for the children, black for us - are printed with the weekend's battle cry: "*Rakai*" - long live life.

"*Rakai*" is also printed on Siriporn's cap. She's turned up the brim at a coquettish angle. Around her wrist are three braided bracelets, exactly like those worn by high school students in Amsterdam, London and Barcelona. Focusing all her attention she paints a picture on her piece of batik cloth in coral blue and yellow: a slender mermaid washed ashore on the beach in Pattaya.

A doctor from Bangkok has come here for one purpose: he will tell her that evening that what she was admitted for in the hospital a month ago was not an allergy but the same virus against which her mother vainly fought.

The face of the grandfather, who doesn't let his granddaughter out of his sight for a single minute, is taut. He wears his red jacket every day, as if he's still cold despite the tropical heat. He allows his hand to rest for a moment on her shoulder. Is it to let her know he's still there, or to convince himself that she hasn't left yet?

We're told to paint a heart containing eight things that are important to us. I usually go to an expert to figure out what it is I'm feeling, but these children have no need of experts. They paint red, green and bright orange hearts with laughing faces, a fish, a car, a house, a flower, a star, a doctor, a cat and a palm tree. A little boy paints a heart with yellow prison bars, then quickly throws a blob of paint over it so all that remains is a dark spot.

Jeeranak paints a big purple heart, and inside it he paints his father, his mother and his oldest brother. They're all gone. A little while later he goes to sit beside a low wall with his back to the others, staring at the sea. I want to walk over to him and push my fist against his, as we did earlier that day, but something holds me back. I can't do it.

Instead I take frantic photos in an effort to hold on to him. I

look through the lens and am shocked to see that far away no longer exists. Far away is close, much too close.

40. World Crayon Conference

The corridors of the Impact Conference Center in Bangkok remind me of a large airport: there are people from all over the world here, most of them carrying small suitcases and bags, women in colorful African dresses, men in long robes, ladies in saris, gentlemen in suits, others in T-shirts. I see a turban, sneakers and shorts, all worn by the same person. I hear Spanish, Swahili, Dutch and most of all a lot of Badly Spoken English, the new international language.

We are all on our way towards the same destination. "Access for All" is written on red banners decorated with elephants that hang all over Bangkok. It's an unreal feeling to be sharing this virus with so many people, people who for the most part look quite "ordinary," people with nothing strange about them, people like me - but in exotic headgear.

When the Gay Games were held in Amsterdam a friend of mine said it gave him such a special feeling to be "among friends" for a few days and not to be part of a minority. At the time I couldn't really understand his feeling; I am me, and that's always a minority, a minority of one.

But maybe things will be different here at this HIV Household Fair. HIV is life-threatening, and for many people it's very unusual to be able to talk about it openly. Most of these people can't even reveal their dramatic situation at home. The one thing really affecting them is kept under wraps, except for a few brave souls who can't keep their mouths shut. Here at the Impact Center the whole idea is that we don't remain quiet; on the contrary, we're expected to speak out, loud and clear.

And so we do. Yet one terribly relevant question - how do we make sure everyone has access to the medicines that can save our lives? - fails to produce an unequivocal answer. Any solution must guarantee

that all the constituent parties benefit. If one party is a big loser the solution won't work; that's just the way it is, no matter how much we'd like it to be otherwise. The big losers today - the tens of millions who have no access to medicines - cannot exercise any real pressure. Their threats are meaningless. A small group of Western activists who think they're speaking on behalf of the powerless by silencing anyone they disagree with certainly won't contribute to a solution. In fact they're just making things worse.

So here I am, "among friends," and maybe for that very reason I feel terribly alone.

I'm thinking about yesterday afternoon, when I was drawing pictures with the children at Mercy Centre, children with HIV, most of whom have watched their parents die of AIDS. I had brought some crayons and colored paper and bags full of chocolates because we were all going to have fun, including me. Tongues protruded in concentration, we drew yellow houses and red castles, blue cars, purple rice fields with orange rivers, green mountains, men with big heads and short arms, princes and princesses with golden crowns, brothers, sisters, a little dog.

At six we ate: rice with chicken and bananas for dessert. Then a nurse came to give us our pills, a handful, one by one. I had brought my own grown-up dose in a plastic bottle marked "evening."

When we had all taken our pills and drawn the sun, never high up in the sky but always half hidden behind mountains or palm trees, I didn't feel so alone for a moment. For a moment I felt "among friends." In my ideal world we're all drawing together and we all take our pills, so we can keep on drawing.

I have to visit my friends at Mercy Centre more often. I need them.

Afterword

In Han Nefkens's columns about HIV there is one particular concern that is expressed in a variety of ways: anger and frustration over the fact that he as a privileged Westerner has access to medicines and medical care, while millions of others infected with HIV have been excluded simply because they were "born in the wrong place."

But a turnaround for Nefkens took place at the fifteenth World AIDS Conference, which was held in Bangkok in 2004. As a connoisseur and collector of contemporary art, Nefkens found a way to make a contribution to the fight against AIDS. He was closely involved in organizing two exhibitions that were held in The Queen's Gallery in Bangkok during the conference. At one of the exhibitions, Thai artists and artists from the wider region showed work inspired by HIV/AIDS, a first as far as Asia is concerned. Then he and the Belgian curator Hilde Teerlinck organized a parallel exhibition at which ten prominent international artists expressed their commitment to the problem in a work printed in a limited edition in the Ecole Supérieur d'Art de Mulhouse/le Quai in France. This work is appearing as a traveling exhibition in several museums in Europe and will be offered for sale as an exclusive portfolio. The proceeds from the sale of these folders will be used to support projects for children with HIV/AIDS in Thailand.

Since the conference in Bangkok, Nefkens has been active in setting up ARTAIDS, a foundation based on the principle of *art bestows life*. Leading international artists are invited to produce works inspired by HIV/AIDS. Not only will the proceeds from the sale of the works of art (important in and of itself) benefit international AIDS projects, but the works themselves, and their presentation, are essential to ARTAIDS. They form an integral part of the foundation's goal, which is to raise public awareness of the HIV/AIDS problem.

The ARTAIDS Fund Thailand makes medicine available to

children for whom the treatment from the Thai government is no longer effective. These new medicines are often only obtainable in other ways or only in doses that are not suitable for children and produce serious side effects.

The stigma of HIV is enormous in Thailand. The Art Camp sponsored by ARTAIDS is one of the few places that offers a safe and relaxed atmosphere where children and their families can discuss their experiences.

In December 2005 the Art Camp was held at the Pattaya seaside resort, two hours from Bangkok. Forty children and their caregivers were invited to attend the camp, at which four artists, including a well-known actor and presenter of children's programs on Thai television, joined the children in painting, drawing, and making sculptures and collages.

Part of the proceeds from this book will be used to benefit Art AIDS projects.

For more information: www.artaids.com

About the author

Han Nefkens (1954) studied journalism in France and the United States. In 1978 he moved to Mexico, where he worked as a correspondent for VARA and IKON (Dutch broadcasting companies) and did radio commentary for VPRO (another such company). He collects contemporary art and puts it out on loan to various museums so it can be enjoyed by a wider public.

He lives and works alternately in Bangkok, Amsterdam, London and Barcelona. His penetrating novel *Bloedverwanten* (Blood Relations), in which AIDS plays an important role, appeared in 1995. Some of the columns from this book were previously published in *HIV Nieuws* and *NRC Handelsblad*.

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