

BORROWED TIME
NOTES ON A RECOVERED LIFE

HAN NEFKENS

Translated by Nancy Forest-Flier

*For Felipe.
And for my father and Lisette.*

CONTENTS

Lucky dog
The kindness of friends
Carrot Day
Father on the phone
Viewmaster 1
It's all bullshit
Preliminary pain
Lucas
Ride
Coincidence
Water
Peeing
Viewmaster 2
Back home
Escape
Tottery
Grains of sand
Aphasia Society
Swiss cheese
Viewmaster 3
The same
Fish instrument
The wrong word
War
Healthy
Viewmaster 4
It's nothing
What could it be
Connected
Full emptiness
The stairs
Viewmaster
Practice
Free theater
The newspaper
The bag
Hat rack
Viewmaster 6
Ground floor
Tricks
Bread
Angry
Angry avocado
Viewmaster 7
Sound off
Nirvana

Passive knowledge
Many happy returns
Viewmaster 8
Cut to bits
One year ago
In a hurry
Naked under my skin
Traveling with a stranger
Viewmaster 9
The front door
Morning walk
Forty euros
Little Children
Anticipation
Funeral on Bali
Stupid
The right button
Clouds of smoke
Viewmaster 10
l'Amour l'après-midi
Virgin
Really unreal
Without glasses
Memory
Emergency exit
Viewmaster 11
Party
Bit by bit
Scratching
Getting attention
Pain
The most beautiful in the world
Real art
Birthday
The bird I used to be

Lucky dog

In October 2001 I was sitting at a sidewalk café in Barcelona, where I live. Suddenly the woman at the table next to mine began to tremble. And not just the woman: her table, the street and all of the Plaza Catalunya had been set in motion. Afraid I was going to fall over I grabbed the back of my chair. And then, just as if it were an earthquake, random incidents in my life began flashing before my eyes. It was like the Viewmaster my parents had given me forty years before after returning from a visit to my grandmother in Geneva. But instead of the Jet d'Eau and the Palais des Nations, I was treated to a haphazard series of snapshots from my own life, images I didn't even know had been tucked away in my brain somewhere.

The trembling continued. My Dutch doctor blamed it on the HIV inhibitors I was taking. I had become an experienced pill-popper by that time. Since 1987 I had worked my way through seven different cocktails, and each new medicine had its own hidden charms: headache, insomnia or a rattled feeling, muscular pain, weakness, diarrhea or constipation, red spots on the skin or a yellowish-brown skin tone, as if I had just come back from a skiing vacation. But this was worse than usual. Like my doctors, I was convinced the culprit was the new cocktail I had started taking earlier that year. There were no alternatives, so I had only one choice: bite the bullet and make the best of it.

I often thought of my mother during those days, who had died three decades earlier at the age of forty-seven. For years she had struggled with cancer, and just as the Eskimos are supposed to have a hundred different words for snow, so my mother had a whole slew of ways to describe her fatigue – 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 can't go on. In 2001 I suddenly

understood how she must have felt, not having the energy to give her five children the attention they needed. That fatigue was a link that connected us through time; my mother and I had become allies. But it was a connection with a twist: I didn't want to be like her – so quiet, so withdrawn, and afterward, at my age, so irretrievably gone.

Maybe that was why I resisted my own fatigue so much, a resistance that cost me every scrap of energy I had. I kept wanting to push things just a little further: ten more minutes on the stepping machine at the fitness center, thirty more minutes of writing, one more phone call, one more e-mail. And that's what I did. I would step off thirty more calories, write another paragraph, call a friend in Mexico, send a response to a gallery owner in Iceland – the way my mother would push herself to take me into town to get a new pair of shoes and my brother to the park to feed the ducks. And like her I'd end up in bed an hour later, sick to the stomach and my head bursting with pain.

In the summer and fall of 2001 I tried to restructure my fatigue with a Zen exercise of my own devising. Sometimes I was able to find rest in the lack of strength, but usually not. My head was full of cotton balls, steel cotton balls. And each week it got a little worse. There was less and less energy left for writing, seeing friends, expanding my art collection, visiting galleries, art shows and artists' studios and maintaining contact with the museums where my work was out on loan. The Zen attitude turned into total exhaustion. I lay on the couch, and most of the time I didn't even have the energy to change the video.

But I was determined to keep going. In August my friend Felipe and I took a trip to Laos and Myanmar. It swept past me in a flurry of images, with only scraps remaining like distant childhood memories. When I got home I tried to work the notes I had taken during our trip into short sketches. I even hoped to write a novel and a novella, but after fifteen minutes of typing I would often have to lie down and

gather enough strength to put my next idea on paper.

I wrote about the headaches, the muscular pain, the general weakness, the tingling in my fingers and feet and around my mouth, the metallic taste, but mainly about the fatigue, the vulnerability it gave rise to, the idea that I was becoming someone else. I wrote about the physical changes: the sunken cheeks, the skinny arms and legs, the shrunken butt, the tummy, the fatty build-up between my shoulder blades, around my neck and under my chin, the high cholesterol level. I tried to keep myself going with the idea that it was just my age. At the same time I thought, Oh, come on, other people are getting older, but I'm still young and I only have side effects to contend with.

My blood was tested but everything looked perfect. The HIV virus had been suppressed and was too low to measure. In the meantime I kept trying to write. It was as if I had emptied out my desk drawers and cabinets of everything valuable and put it all in a trunk. All that was left were bits and pieces, fragments of a fading life. Without knowing it I was getting ready for a journey – but I had absolutely no way of knowing where that journey would take me.

And then, on that October day, the trembling began. First it was barely noticeable, as if I were standing in a gentle breeze. But gradually it became more intense – not only did my head pound but my whole body shook, as if I were standing next to the boiler of a gigantic freighter. In November, when I told my Dutch doctor about the trembling and the persistent paralyzing fatigue, he told me to stop taking my medication without delay. He suspected that what I had was a serious form of medicine poisoning, a poisoning that could be fatal. For the first time in more than fourteen years I discontinued my rigid routine, which involved taking medicine three times a day at exactly the same time. I thought I would start feeling radically different – that the real me, one that had not been deformed by side effects, would come to the

surface. But nothing could be further from the truth. The symptoms quickly grew worse. A fog formed in my head that separated me from the reality around me. I was too tired to worry about it – all I wanted to do was close my eyes because the light in my room was too harsh, even with the shutters down.

In early December we moved. It literally passed me by. While Felipe and a girlfriend of ours gave the movers packing instructions, I stayed in a hotel opposite our new house, the house that I wouldn't enter for the first time until three months later.

By December 7, a few days after our move and two months after the world had started trembling at the sidewalk café, I was practically unable to speak. Walking upright was also something I could barely manage anymore. Felipe called Joep Lange, my doctor in the Netherlands, and he got on the next flight to Barcelona to take me to the Academic Medical Center in Amsterdam.

Now I'm in good hands, I said to myself on the way to the airport. Now everything will turn out all right. But the doctors had no idea what had gone wrong, so they didn't know what to do to turn things around.

Within a few days my condition had deteriorated noticeably. I was hardly aware of what was going on around me. The doctors were afraid I had a brain tumor, but after a week of extensive testing they came to the conclusion that I was suffering from a reaction to the sudden withdrawal of medicine: my brain was being bombarded by the HIV virus. This bombardment had resulted in encephalitis, a life-threatening inflammation of the brain. Encephalitis is not uncommon in the last stages of AIDS, but with today's HIV inhibitors it rarely occurs in the West.

I was totally oblivious to everything. When Lisette, my father's wife and my loving third parent for more than thirty years, told me there was good news – that I didn't have a brain tumor after all – I

started to laugh. What did she mean? Was there something wrong with me?

I was as 'demented as a loon,' to quote my doctor. For weeks I teetered on the brink of death. But then the tide turned, and the period of recovery began.

It was as if my hard disk had been erased during those few weeks. I could hardly remember what my name was. I couldn't eat, drink, go to the bathroom or take a shower without help, and I couldn't dress myself. Whenever I put my feet on the ground the floor would start to spin and I would lose my balance. Everything I had once taken for granted had to be learned all over again. Walking is complicated when you no longer know what leg to start with and then what to do with the other one. Eating a cheese sandwich was an impossible challenge: not only did I lack the strength to cut the bread into pieces and bring the fork to my mouth, but I didn't even know where to begin.

But that was nothing compared with the powerlessness I felt because the words had gone into hiding. I knew they were somewhere in my head, but I couldn't get to them – the harder I looked, the more confused I became. The words that did rise to the surface weren't connected to any particular image. They were words without meaning, as if they were from a language I didn't speak. "Wednesday" meant the same thing as "buttermilk," "pillow case" was "strawberry jam." My head was empty. Every now and then I'd hear an echo, but what that echo was I really couldn't tell.

When I was released from the hospital in February 2002 the neurologist said it would take a couple of years before I was my old self again. I nodded, but I was convinced he was wrong. Maybe it took other people with aphasia that long, but I was going to be back in shape in no time.

As it turned out, my doctor was right. It took at least two years

before I could function reasonably well, and even now, more than five years later, there are moments when I can no longer remember the name of the friend standing next to me. Every now and then when I arrive at an airport I have to ask myself where I am and what I'm doing there. And sometimes I can't recall the face of the person I'm speaking to on the phone. All these incidents happen sporadically enough that I can reassure myself with the thought that it's my age, and that other fifty-three-year-old people struggle with short-term memory loss, too. It has nothing to do with the moment the HIV virus affected my brain, turning me from an adult man to a two-year-old child from one week to the next. "The past is over," I say out loud to myself at times like that. "It's over and done with."

But if that's true, why do I keep crossing to the other side of the Herengracht when I get close to the hotel where I spent a month after my stay in the hospital? Why do I no longer eat the bakery-fresh muesli buns that once kept me alive for months? And why does it take so much effort to read what I wrote five years ago?

Even before I could really talk again I crept back to the computer. I wrote in a trance. My fingers were being sucked toward the keyboard. Most of the time I didn't understand what was appearing on the screen, even though I had written it myself. Reading was a trial. Sometimes I would re-read a sentence, but by the time I got to the end I had already forgotten what was at the beginning.

It reminded me of my first weeks after moving to Mexico in the summer of 1978. I didn't speak any Spanish, but I very much wanted to participate in the life there. Every morning I bought a Mexican newspaper at the stand on the corner of the street where I had rented an apartment, and I went to a sidewalk café to read it. I understood some of the words, but what all those words were doing together in a sentence was anybody's guess.

That's just the way it was during the first eighteen months of my recover. I understood most of the words I had written; I just had no idea why I had put them together in a sentence and what I was trying to say. It was like being two people in one: someone who was trying to hold himself together by hook or by crook, despite the shaky legs and the apparently slanting streets, and someone else who stood back and wrote about it like a person under hypnosis. As soon as I stored my writings in my computer archive, the sketches I wrote and the observing person were gone.

Now, more than five years later, I'm back to my old self as far as the outside world is concerned. But for me there's a difference. A number of things that disappeared during the bout of encephalitis – fears, inhibitions, bad memories – are gone forever. I'm now less afraid and extra enthusiastic about doing what I think is important: writing, giving good art a chance and doing something for my fellow HIV sufferers who have no access to the medicines that have saved my life.

There are still two opposing forces wrestling within me, even after the passing of five years. On the one hand I'd really like to forget the entire episode. I don't want to talk about it anymore or think about it anymore; I want it not to have happened at all. I cough uncomfortably when my youngest sister tells me I didn't recognize her when she visited me in the hospital, and I look away when a friend says it's unbelievable that I'm completely recovered. At the same time I realize how special it is to be one of the few who have returned from this long journey to a desolate and unknown land. Most of my fellow travelers are not able to recount their adventures, but not only have I learned to read and write again but I can also tell it like it was. The price of this restored ability is that I actually have to do it, no matter how difficult it still is for me to write these words and – a hundred times more difficult – to re-read them.

It's incredible that I'm still here, something I fully realize every single day. Sometimes I miss those first years of recovery, when I was living completely in the present moment. I was free as a bird back then, and I remember it with a faint wistfulness. Now I know I'm just a lucky dog. I'm living on borrowed time, and writing this book is the interest I have to pay. It's worth every cent.

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 say to myself, all of them here for me. I've really got to make some kind of contact. 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 his head," says a worried friend, pulling up her chair so as not to miss any first word I might utter.

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

Bitch! We can strike her from the visitors' list. She's too clever by half. 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.

One friend sighs. Another one coughs. Yet another whispers something, very hushed and respectful, the way you do in church or in 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 just enough of my wits to know that that's the one thing I shouldn't say. So I don't say anything.

"They seem to be aware of their surroundings. That's what they say about people who've been in a coma for months, too," says the friend who isn't allowed to come here anymore. "They do appreciate it."

The others nod. They're not allowed to come here 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.

One thing I know for sure: if I get better – *when* I get better – I’m choosing different friends. Friends who don’t come to see me when I’ve got encephalitis. Friends who know there’s only one way to respond to silence, and that’s to show solidarity by keeping your own mouth shut.

Carrot Day

Every morning a doctor comes to my bed to ask me several questions. He’s trying to figure out if I’m demented or not, based on my answers.

“Do you know where we are now, Mr. Nefkens?” he asks.

“In the AMC.”

“And where is the AMC?”

This is a trick question and I’m ready for it. If I don’t know where the AMC is it’s proof that I’m certifiably demented. “The AMC is in the AMC.”

No argument there. Even so, the doctor still isn’t completely convinced. “Do you know what month it is?”

I pull a face as if I’m opposed in principle to answering such dumb questions. But the truth is I have no idea what month we’re in. The Christmas decorations on my night table don’t help at all. The New Year’s card doesn’t help either. Even when the doctor points out that there’s snow on the ground, I still haven’t got a clue what season it is.

The doctor isn’t good at keeping secrets. At the end of what he calls a conversation he tells me it’s December, that tomorrow will be New Year’s Eve and that it’s snowing outside because it’s winter.

The next day he asks me exactly the same questions and I still can’t give him a single answer. Once again, none of my lights go on at the mention of December 31st, Christmas and winter. The doctor could just as well have said that it was beets – the 31st of Beets – and that the next day we’d be celebrating Carrot Day, and that this was the season of goldfish. It all would have meant the same to me: that is, nothing.

It’s unreal when your own language has become a foreign tongue to you, when words like “New Year’s” or “winter” don’t ring any bells

in your head. It's strange when words lose their meaning, when you no longer recognize the word "word" and the word "meaning," when "word" might also be a thing you eat your soup with, and "meaning" what you wipe your butt with when you go to the bathroom.

It's strange to try to imagine what something is like when you don't know what it is. How do you imagine nothing? Kind of empty and bare. That's what it's like – empty and bare, but restless at the same time.

Father on the phone

"Your father is on the phone."

The nurse presses the receiver into my hands. I look at it with astonishment. What am I supposed to do with this thing? She raises an imaginary phone to her own ear and nods to spur me on. I follow her example.

"Hello Han, it's your father."

I don't understand what this is all about, and I lower the receiver. The nurse picks it up.

"Your son is right here. I'll put him on." She presses the receiver to my ear.

"Hello, Han, your father here. How's it going?"

I stare vacantly at the nurse while my father does his best to talk to me.

She takes over the receiver. "Your son really is here, Mr. Nefkens. He'll say something in just a minute."

I'm given the telephone once again and hear my father call, "Han, it's me, your father. Han, can you hear me?"

I drop the receiver.

"Your son isn't quite up to saying anything right now. I'm sorry, Mr. Nefkens."

From far away I hear my father calling my name. The nurse takes the receiver and hangs up.

Viewmaster I

I'm suspended above the breakfast table in the house where I was born. My mother picks me up so we can wave good-bye to my father through the window. He laughs and waves at me with his hat. Then he gets into a big black car. My mother presses her cheek against mine. She's grabbed my hand and is making waving motions with it. I see the red flowers on the rusk tin next to the butter dish. For years I've been looking for that very same rusk tin, but I've never been able to find one.

It's all bullshit

The nurse is standing in a corner of my room, organizing my daily medicine into little containers. Nine for right now, four for two hours from now and fifteen for this evening.

His fellow nurse is looking on.

“What exactly do you say to someone who's been lying in bed for weeks and doesn't open his mouth?”

“Oh, I just say whatever comes into my head. It's all bullshit, but he doesn't care.”

I blush with vicarious embarrassment. And then I know: I'm starting to get better.

Preliminary pain

It's all awful, but the mornings are the worst, the early mornings. You can hear them coming, those mornings. They rattle and jingle and let you know that you've got a whole day to get through. They come to wash you in the mornings. Or they come to tell you that they're going to wash you soon. That's the worst – not the torture, but the announcement of the torture. The preliminary pain, the pain that comes before the pain itself.

You just lie here and wait till it's over. All over, for good, without your being dead. That's what you wait for.

There are various events that mark the passing of time. They're like milestone that the waiting is attached to. Being woken up is one milestone, getting washed is the next one. Another milestone is breakfast – in my case a useless milestone, since the breakfast is put down in front of me but I can't eat it myself. So I have to wait until a nurse comes to feed me. But they're much too busy knocking off the milestones to feed me. The breakfast has to sit there for a while, until the cheese starts to sweat and the edges of the bread get hard. Just when the breakfast isn't good anymore, when it's too soggy to eat – that's when it's time to feed me. A bite for daddy, a bite for mommy, a bite for Han who's forty-seven.

But age doesn't mean anything anymore either. It's just another milestone, a useless milestone that time gets hung on. It's a soggy sandwich, sweating cheese. I'm forty-seven, but there's no difference between me and a twelve-month-old baby. I'm just as helpless and I know just as much.

So I wait. For the next minute. The minute when the preliminary

pain stops and the real pain starts, so I can wait for the minute when the real pain stops.

Lucas

Lisette tells me that my youngest sister has had her second child, a boy named Lucas.

I look at her. I know she's telling me something special. I can see it by the look in her eyes. She's brought her face up close to mine and holds my hand as she tells me. "This is just the sort of message that you're expected to respond to," I say to myself, but I have no idea what it means or what the appropriate response is.

I try to say the name. My lips move, but no sound comes from my throat.

Lisette smiles and presses a kiss on my cheek.

Ride

Every morning I'm on the lookout, sitting up in bed and waiting for Felipe. He's the only one I talk to, in Spanish. He comes at around ten o'clock with molasses waffles, oranges and muesli buns. Most of the time I can't even remember my own name, but the only muesli buns I'll eat are the ones from the bakery on Runstraat. One time Felipe came with buns from Albert Heijn, but I pushed the package back at him: Albert Heijn *no*, Année *si*!

When I finish my muesli bun, Felipe pushes my wheelchair through the entire AMC. The medicine makes me itch all over, and I'm restless – riding around is the only thing that helps. An hour and a half later and completely out of breath, he rolls my wheelchair back to my room and asks me what I want to do now.

"Ride, but a little faster than just now because my legs are itching again."

Felipe sighs, grabs the wheelchair and pushes me toward the elevator. We haven't done the fourth floor yet today.

Coincidence

They're standing together in my room: my brother from Curaçao and my best friend from New York. They've known each other for more than thirty years but they haven't seen each other in a long time.

I can talk a little now, and I remark what a coincidence it is that they're both in the Netherlands, just when I'm here in the hospital.

They look at each other with surprise but don't say a word.

Every day they drop in, for weeks, until I'm released from the hospital. That very day they both leave. And I continue to be amazed by the coincidence.

Water

The car pulls out of the AMC grounds. I start crying, but I have no idea why. We drive to a chic hotel on the Herengracht where I'm supposed to recuperate until I'm strong enough to travel back to Barcelona. As Felipe fills in the forms I throw my arms around the surprised receptionist's neck.

The pleasure doesn't last long. Suddenly I'm scared to death of water. I refuse to take a shower and I refuse to drink. Felipe is at his wits' end. I have to take my medicine, it's my only option. If I skip a dose I could become resistant, and there are no other medicines available.

Felipe pleads with me to take my medication. But I – who have been downing my daily pills punctually with the discipline of a Prussian soldier for fifteen years – shake my head. I don't understand why he's making such a big deal out of this. After all, there's nothing wrong with me. With tears in his eyes Felipe explains that I'll have to go back to the hospital and be re-catheterized if I don't take my medicine right now. I look at him and start laughing uncontrollably. I don't know why. I don't even know that what I'm doing is laughing. Felipe shuts himself up in the bathroom, after which I hear noises that sound very much like my own laughing fit.

That afternoon I'm re-admitted to the AMC.

Peeing

I have to pee, so I climb out of bed. When I get to the middle of the room I stop, next to the bathroom door. I know that peeing and bathroom have something to do with each other, but I can't remember what it is. I also don't remember how you're supposed to pee. I've done it before, I'm almost sure of it, but what the exact procedure is I haven't a clue.

The pressure on my bladder is mounting. I squeeze my knees together and pace back and forth across the room as best I can, grabbing onto the bed and the chair near the table. I stand there for what has to be the good part of an hour. My bladder hurts, my legs are shaking and I don't know what to do.

Just as the nurse walks in, after I called for her half an hour ago, I can feel the pressure on my bladder disappear and my pajama pants becoming wet and soft. Drips run down my leg.

My release from the hospital is being postponed for the time being.

Viewmaster 2

I'm standing in the bushes on the playground, gazing at my classmates. They're laboring over a dictation exercise. I'm not playing hooky so I can take a stroll through town or go to the pool. I want to look through the window at my classmates. I want to know what it looks like from the outside.

The teacher says something. I can't hear her. I can only see her lips moving. She articulates with exaggeration, as if she had a bunch of deaf mutes in front of her. The children are bent over their notebooks, a class full of strangers – although I know each one's name – and a strange teacher. Now that I'm out here looking in, the strangeness isn't so bad any more. The bad thing is being in there among them and knowing that I don't belong.

Back home

We come home to an apartment full of crates and boxes. In December we had no time to unpack – five days after our move I was so sick that I had to be rushed to the AMC.

Now, three months later, I'm lying in a darkened bedroom (I still can't tolerate light very well). Felipe is unpacking the boxes with the help of a girlfriend who came here from Mexico to give us a hand.

"Forget about the boxes," I shout from the bedroom. "I want all my photos and paintings on the wall now, right away."

I already know where everything has to go. Felipe and Ingrid have been at it all day hanging up the Bernard Frize, the Zandvliet, the Shirin Neshat and the Jörg Sasses. When they're done, I'm satisfied. They can leave the boxes. All I need is my art.

Escape

I don't want to talk about what happened. Nothing happened, so there's nothing to talk about. But sometimes Felipe tells me something. Like yesterday, when we were sitting on the balcony of our apartment with our dog Ollie at our feet. He told me that one time I got up in the middle of the night, put on my jacket over my pajamas and walked to the hospital entrance. There I got into a taxi.

Just before the taxi drove away someone on the ward sounded the alarm. The night watchman was just able to get me out of the car.

Where would I have ended up if the night nurse hadn't discovered half an hour later that I had escaped? What language had I spoken to the cab driver, what address had I given? Where would I be today?

Tottery

I didn't slip in the shower this morning, I tottered. I had to grab onto the soap dish, and I thrashed around a few times, but I didn't fall. That's the big difference between now and five months ago when I couldn't shower by myself, couldn't dress myself, couldn't feed myself, couldn't do anything by myself. And there's a world of difference between now and ten months ago, when I'd jump under a cold shower after my morning training session, all fresh and ready to write.

My life was stolen from me the minute I turned my back. I continue to marvel at how smoothly everything once ran and how awkward it all is now. It's not only the practical awkwardness of not being able to do so many things, or only being able to do them badly. I miss the support of the good old routine that got me through the day. I used to draw strength from the most insignificant activities. I could take the world on when I went for a walk with Ollie to buy a newspaper at the stand on the corner and to pick up fresh baguette from Escriba the baker. The ritual of reading the newspaper with my cup of green tea and turkey sandwich with avocado – three slices, every morning – imparted a sense of tranquility and trust to the day. Now before I go out on the street I have to overcome the fear of falling. I can't prepare my own breakfast and I can't read. I've lost the comfort of my routine, and there's nothing to hold onto anymore. I'm lost in my own world.

I've got to re-conquer everything inch by inch. Nothing happens automatically. It's hard to find satisfaction in re-learning something you could do a year ago, something you took for granted.

Taking things for granted. Even saying that requires an enormous effort now.

Training, taking cold showers, writing, reading, enjoying my

food, walking upright without tottering – I miss my old life. I miss my life. I miss myself.

Grains of sand

I have to ask Felipe: where were we a year ago? He answers, we were in Vietnam and Cambodia. And Bangkok. I steal a glance at the papers to see if he's right.

It's as if part of my life had been swept away, as if entire files had been erased by a computer virus. Felipe talks about what I said and did, but he might just as well be speaking about someone else. It's totally foreign to me. It's got to be in there somewhere, but I can't find it. At the same time, the computer virus has invented different files. So what's real? And if the files that seem real aren't real at all, what about me *is* real?

If you don't have your memories anymore, then each moment is on its own. It's totally disconnected from the preceding moment, even though it issues from it. But moments on their own have very little meaning; they only mean something in relation to what happened before and what is yet to come. They acquire meaning from the person who imposes meaning on them. For me, all the moments now are individual grains of sand that don't form a beach but a chaos of grains, a confusion on which I'm trying to impose meaning. I'm not having any luck, and my own life is slipping away.

Aphasia Society

Felipe looked it up on the internet. We're going to a meeting of the Aphasia Society, because aphasia is what I have. That's why I almost never talk. That's why I don't understand the meanings of words. That's why I can't read, not even a short newspaper article, not even the writing on the package of cornflakes, and that's why I can't understand any films. I see the moving images, but I don't understand what the one image has to do with the other image. After three minutes of watching TV I get bored.

Felipe takes me to the Aphasia Society meeting. He does all the talking and answers the questions about what exactly happened to me, about what shape I'm in now.

At the end of the conversation the fat woman says, "I haven't heard Han himself yet. Do you want to come, Han? Do you want to learn to talk and read?"

I nod, but I realize that's not enough. And with a hoarse voice I say, "Si, quiero. Yes, I want to."

Swiss cheese

My head has turned into one big Swiss cheese that consists mainly of holes. It's pretty empty up there with all those holes. It's windy. Drafty. You've got to eat your way around the holes if you want to taste anything, and that's the tricky part. Because each time I end up with another mouthful of nothing.

My speech therapist says that the cheese grows around the holes. The holes stay where they are but the cheese paves a new road for itself. That's easy for her to say with her Gouda head – a head without holes. “If you just practice enough the cheese grows all by itself,” she says, and she shows me those three pictures and asks me to make up a story about them. A shovel, a croissant and a pink garden hose. If I can just see the connection among these three things, my Swiss cheese will grow back together all by itself.

I'm on the beach and I eat six croissants, so I can take my shovel and the pink garden hose and build an enormous sand castle.

“You see, it works,” cries the speech therapist, lisping from pure emotion. I feel my cheese growing. The holes are shrinking by the day, bit by bit.

Viewmaster 3

Standing in my shorts and yellow striped shirt on the grassy vacant field in front of our house in a quiet Rotterdam suburb, I'm watching a plane fly over. I'm trying to imagine that I'm in that plane, that I'm looking down and fantasizing that I'm a little boy looking up. This puts me in two places at once. I know I can do this, I'm positive, if only I try hard enough.

The same

“You’re exactly the same as you were before it all happened, before you got your wires crossed,” says the speech therapist who’s teaching me to talk again.

“That’s odd,” I say to myself, because I don’t feel the same at all. I feel like a different person, a stranger. The person who could read and write, the one who strung words together and saw new connections in them – that was me. Not the person who’s sitting here and taking everything in with utter amazement.

“But how are you so radically different?” my speech therapist asks.

I have to think about that one.

I’ll only be the same again when I can say in words why I’m different. But before I can find those words, the forty-five speech therapy minutes are up.

Fish instrument

Only when I see the speech therapist’s pictures do I realize how much I don’t know anymore. That instrument with a hook is used to catch fish. You put it in the water, and when you have a bite the fish tugs on it. But what’s it called again? It’s a fish instrument, but it also has a name.

A lot of things don’t have names for me anymore. They have a function – I know what they’re for and I can write about it at length. But there’s that one word, and I’ve forgotten what it is. Actually, “forgetting” isn’t the right word. It’s not forgetting. I just can’t get near it. It’s like lending something, but then the other way around. It’s gone for a little while, but it’ll be back soon. My whole day consists of waiting for things that have been lent for a little while to come back by themselves.

The speech therapist has a pile of photos of things that come back by themselves. There’s a thing with pincers that you use to fasten your belt with, and there’s a mountain of soft stuff that makes me sneeze, even without knowing its name.

I propose that in the meantime we take a break and do something else. A head full of things that aren’t quite there but are coming back soon is boring. I propose that we read something. I’ll read aloud, and as long as I read what’s there I can keep on reading. That sounds less empty than the things that are out on loan.

The speech therapist thinks that my wanting to read is a good sign, so she picks up a thin book with very large letters. It’s called the King’s Magic Wand. You shouldn’t start off with something too hard, she says. She puts away the pictures for the next time. There will be plenty of opportunities to practice.

The wrong word

Talking is a trial. Walking, adding numbers or remembering – everything I have to do but can't – is cruel. Writing is a comfort. But with all those vanished words, writing is like playing on a guitar without strings. I can only rap out a rhythm like a drunken gypsy, beat time without being able to keep up with it myself.

The words that appear in place of the vanished words are the wrong words. I'm a man with the wrong word in the wrong place.

War

Sometimes someone tells me what I was like back then. Not so great, I gather. It's like hearing a story about the war, a story about a time before I existed. I feel sorry for the people who lived through the war. I try to imagine what it was like. But it's not my experience. It didn't happen to me.

I don't tell them that I feel sorry for them. I still don't talk very much. Writing is easier for me. When I'm at the keyboard, the words escape less easily than when I pronounce them. When I talk I have nothing to hold onto. I get to the middle of the sentence and forget what I wanted to say.

Felipe talks about my hospital period, about what it was like. I ask him how many people I shared the room with. "First there was no one else," he replies. "For the first six weeks you were alone. And then there was another gentleman."

If he were to claim that I had shared a room with twelve dwarves, I'd believe him just as much. Of course what I really wish is that he'd say, "Hospital? What hospital? I don't know what you're talking about. You've never been in a hospital in your life." All I'd have to do then is wonder why I get such a strange feeling in my stomach whenever I get anywhere near the AMC.

Whenever I tell myself that it did happen to me, that I did fight my own war, I get very angry. "Don't lie like that. It's so morbid," I say to myself. "I can't believe a word you say, and I'm not going to listen to you until you speak the truth." I put my fingers in my ears and refuse to listen. I don't want to believe myself.

But every time I notice that it's not going well at all, when I sway and totter, forget something, lose my way in my own house, in my own head, whenever I have difficulty reading, then I get angry. Seething.

Because each time it's new proof that it really did happen. And I don't want that.

I don't remember how many people I shared a room with, and I don't want to know. When I do find out and don't get angry anymore, I'll know I'm doing better. Then I'll be able to go back to ordinary writing about fashion magazines, about a non-existent Dutch neighbor and a non-existent Catalan president who wouldn't allow the air conditioning to be turned on. When I no longer get angry I'll be able to make up stories and spin a good yarn. Until then I'll have to be satisfied with what really happened.

Until then I'll have to be satisfied with what I don't want to believe.

Healthy

I've never had this before, wondering whether I'm crazy or not. I used to be nuanced in my thinking. Everybody has a little of this and a little of that, I used to think last year. It's absurd to put a label on it. And who wants to be like everybody else? I was convinced that I wasn't crazy, and I decided that everyone who thought I *was* crazy was nuts himself.

Now I'm not convinced of anything anymore. Now I wonder about everything, even about my own mental health. I'm not as stable as I used to be. But I was always this way, except that in the past I could hide it better. I kept my entire existence under tight control, and all my attention and energy were focused on maintaining that control.

I don't do that anymore. I can't, for one thing, and I simply don't want to. I'm leaving it as it is, and everything inside is coming out. It's a messy, chaotic business, and for everyone around me it's mainly an overdose of Han. For me, too. But it's all there is, and I insist that it's a million times better than the alternative: no Han at all.

When I consider the fact that that's almost what happened, that I almost didn't make it, it makes me howl with horror. It's retrospective crying for what took place. When it was actually happening, I sat off to the side and watched. It's as if I'm only really feeling it now. The effect was severely delayed, but that doesn't make it any less intense. I – who never shed a tear before, I – who was so strong and had everything under total control, now I'm howling and raving.

I don't know if I feel more than I used to, but I do know that I feel more strongly. It's as if the space that used to be occupied by thinking is now occupied by feeling. There's a lot of it, and it's very strong. Sometimes I stamp my feet with rage over what happened to me. Knowing that I almost died makes me hopping mad. It's not fair! I don't want this! I didn't want it then, and I don't want it now!

The more I think about it, the more I come to the conclusion that I'm not crazy, not even slightly unbalanced. I'm perfectly right. What happened to me is enough to make me howl and stamp my feet – and the fact that I do those things, now, nine months later, is just a good sign. Better late than never. I'm not crazy. I'm the picture of health.

Viewmaster 4

It's a balmy evening. I'm standing in front of our 1930s house on a stately avenue. The striped awnings are hanging down as if the house were shutting its eyes, blinded by a sun that even now can scarcely be seen. Despite the beautiful weather the street is empty and our house seems uninhabited, although I know that my three brothers and my sister are in their rooms and my mother is resting on the couch, waiting for my father to return from the office.

It's quiet, deathly quiet. Suddenly it hits me. It starts at my feet and slowly creeps up until it reaches my stomach: a chill that burns, a freeze that doesn't fade. On the contrary, my hearing has become more acute – the warbling of the birds, the voices in the distance, the buzzing of a bee, a dog barking somewhere far away. My sense of smell has become more acute – the leaves on the trees, the wet grass, the sweet evening air. That warm evening weighs on me so heavily that my legs start shivering and I have to sit down on the edge of the sidewalk.

It's not only the heavy feeling itself that has caused me to sink down; it's also the knowledge that the feeling will never go away, that it's nestled inside me for good, to fuse with who I am. I know I'll have to find a place that doesn't resemble this one in any respect, somewhere in the world where the place where people should be isn't so terrifyingly deserted, where the place where life should thrive isn't so appallingly quiet.

It's nothing

There are days when my skin feels raw, like a wound without a scab. Everything hurts, including nothing – especially nothing. The dog that barks, a car door slammed in the distance, the frown on the brow of the lady in the bakery, the wind, a cloud in the blue sky that's just a little too big, the phone ringing, the phone that doesn't ring – everything burns. Nothing hurts, too – especially nothing.

I know. It's nothing. That only makes it worse, so I want scream from the pain of nothing. Experience tells me it will be gone by tomorrow. Tomorrow I won't even hear the barking dog any more. So it's a question of getting through the day without listening to the lament in my stomach. There's only one way to do that: my lament will have to move from my stomach to my computer screen. Whatever is inside me, the gnawing complaint, has to be transferred to black-and-white. Only then can I see it for what it is: nothing. Only when it's no longer in my stomach will I be rid of it.

What could it be?

The speech therapist says it's quite normal for people to change after something dramatic has happened to them. She says this between two pictures: one of a cream pie and one of something else whose name I still don't know. She says that people can sometimes get very angry all of a sudden, even if they'd never done that before, or can burst into tears, even if such behavior was totally foreign to them.

It reminds me of a few weeks ago, when I angrily stood up from my table in the La Principal bar, seething because they brought me what I had asked for when what I meant was something different. And I recall how I burst into tears that morning in some bar because I was suddenly so moved by the muzak rendition of "The Shadow of Your Smile." If this goes on, I won't be able to go anywhere and we'll have to move once again to another continent.

I ask the speech therapist what causes those changes in mentality: damage to our brain or the fact that we've experienced something dramatic? She doesn't really know; maybe both, she thinks. "Both" is what people always say when they don't know something. It can be one or the other.

I find it strange that this happens to me, but the fact that I really don't care what other people think when I rage or howl strikes me as even stranger. I really don't care, and that indifference sometimes makes me laugh out loud. I rage and howl, but at the same time I have to laugh at the person I've become.

"You use it to pitch a tent, to secure a boat in the harbor or to hoist yourself up when you're climbing mountains. They even used to use it to hang people, but fortunately that doesn't happen anymore," says the speech therapist as she taps on the second card.

"It's different in Spanish than in Dutch," I mutter, and I wonder

what the Dutch word is for the thing they tie around your neck when they hang you and then use to secure a boat.

Connected

The odd thing is that when I remember the Spanish words, the Dutch and English words come back, too, as if they were all riveted together. If I don't know a word in one language, I don't know it in the other languages either. But if I discover *boom*, I find it's connected to *arbol* and *tree*. *Lepel* is connected to *cuchara* and *spoon*. Three for the price of one – four, actually, for when I visit an acquaintance in Paris and explain that I can't speak French anymore because of my encephalitis, and tell her how much I regret this because it's such a beautiful language, she points out that I'm saying this in fluent French.

So I speak the language all right. The words are there. I just don't know they're there.

Full emptiness

Like hugging a lost child so he won't run away again – that's what I do with words when I recover them. Black on white, I store them in my computer archive where they're safer than in my head. Except if my computer were also attacked by a virus. That electronic HIV would destroy everything I've got, because I don't have a back-up or an external hard drive. If that were to happen, an emptiness would form like the one in my head, an emptiness so full that nothing else would fit in it, not a single thought, not a single word.

Fearing such emptiness, I grab hold of everything I think and quickly write it down. I'm not going to lose it a second time, that's for sure. I'm not going to be left behind with nothing.

The stairs

I saw it the minute I got out of the elevator: there's something wrong with the stairs in the hall. They're going to be repaired soon. Until that happens we'll have to make do without the first two steps and half of the third, and the railing is gone.

Stairs are my weak point right now. I have visions of tumbling down the stairs -- and they're not imaginary visions, either, because I've been doing a lot of tumbling lately even without stairs. Fortunately the stairs have railings for me to hold onto. I'm a great believer in railings, even when there are no stairs. A railing is something everyone has a need for, even on the ground floor.

When I come to a set of stairs I push myself against the wall and firmly latch onto the railing. Then I slowly lower myself down, step by step, with a nonchalant expression as if this were all quite normal. But when there's no railing, or no wall to push myself against, that's when it gets difficult. So I've made a deal with myself that this is a no-go situation and that it's better for everyone if I leave the stairs alone and go do something else.

And that's what happened today. No big deal. We're just not going outside today. I'm calling the dog-walking service to come for Ollie. Not that I'm going to let myself be thrown by some insignificant detail. Actually a couple of broken steps and a nonexistent railing don't faze me in the least, but why make life unnecessarily complicated?

So we turn around, the ninety-four-year-old neighbor man and me, and we both take the elevator back up. Going down the stairs and walking outside – you don't need to make a habit of everything. With a bit of luck the stairs will be fixed by tomorrow. If not, Monday then. The weekend will be over before you know it.

Viewmaster 5

I walk through the movable gangway at Schiphol and feel like a snake shedding his old skin. Thirteen hours later the plane cleaves the gray-brown blanket of smog; Mexico City is the color of a faded photograph. The horizon keeps shifting, yielding to more and more buildings, more highways, more towers. I follow a black spot passing over the houses and streets. Only after a while do I realize that it's the shadow of my own plane.

As we land, brushing past high rises with laundry hanging on the roofs, I see a big billboard with only a name on it: Yaco. I ask myself what it is: soap, a yoghurt drink, the name of a locally known singer? I cherish this ignorance. It's proof that I've descended on a completely different world.

Practice

I'm having my first power lesson with a female trainer who is also a physical therapist. What I want to do is develop my muscles. I want to get strong so nothing can ever happen to me again. The physical therapist listens attentively to me and suggests that we start slowly with a few walking exercises.

"This ought to fill up that sixty-euro hour in no time," I say to myself, and proceed to fall over.

I have to walk upright without looking at the ground and without falling over, but I can't do that.

"I don't want to walk upright," I scream at the physical therapist. "I want muscles. I want to get strong."

"Sounds good to me," says the physical therapist. "Let's try walking once again. Just hold onto me."

We try it once more. I totter and sway. I almost fall over but manage to grab her shoulder just in time. I try it again, now without holding onto anything, and fall flat on my face.

I'm forty-eight years old and I have to learn to walk again. I don't care if I do or I don't, but I have no idea what the alternative is. You have to walk. No one ever asks whether you feel like it or not. They don't ask what you prefer, fish or chicken or vegetarian. Life is no Singapore Airlines. Life is a treadmill, a treadmill that never stops – until it stops for good, and that's no good, either.

Today I'm going to do my exercises at home. One leg up and the other leg down, or vice versa. Fortunately my physiotherapist has written it 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. While I'd much rather run.

Free theater

I don't go to the theater anymore. I visit the Aphasia Society waiting room four times a week, and no performance can beat that. It's a feast for the eyes and it doesn't cost me a thing.

Yesterday I was there for an hour, between my lesson to learn to read again and my lesson to learn how to vent my feelings. The wife of a fellow aphasiacs said her husband had gone to speech lessons. Two months ago he had a stroke and now he can no longer talk. She said he gets angry when she doesn't understand him. He starts shouting, 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 very, very angry.

The waiting room of the Aphasia Society is the only place on earth where the people are angrier than I am.

Jose Luis has been coming to the Society for five years. Five years ago he could neither walk nor talk. Now he can move around and make noises. A word to the wise (even a couple of noises) is sufficient. He makes a sound like a vacuum cleaner and we all know he means speech therapist.

Mr. Pereira can sing beautifully. He doesn't have enough vocabulary to hold a conversation, but he knows the lyrics to all the songs he's ever learned.

"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 enthusiastically and looks happy, with those big green eyes of his that always seem as if they were about to disappear into his face. He may not know his granddaughter’s name any more but that doesn’t mean he’s forgotten her.

I’m glad I know the difference between a month and a year. I know that time passes in a certain way, although I don’t feel the passing as strongly as I used to. It’s like some people who divide time into the period before and after the war; my life is divided into the period before and after December 8, 2001.

Mr. Pereira strips words of their value. A month, a year, a name – the things that mean so much in daily life don’t mean anything to him anymore. He doesn’t like to talk. When he does say something, the non-aphasiacs immediately start asking about what it means and whether it’s correct or not. They never ask about what he’s really saying: that he’s crazy about his granddaughter.

We often dislike the things that we could do before the war. You’re never thrilled by the things that require a lot of effort and that you can’t do very well.

Mr. Pereira, José Luis, David, the man who gets so angry at his long-suffering wife, me – we all have our place in the waiting room of the Aphasia Society. I belong here. It’s home.

The newspaper

“You have to buy the newspaper every day,” says my speech therapist. “You’re certainly up to it.” It was an order. So today, for the first time in ten months, I bought the newspaper. Or was it eleven? Counting is still a bit difficult for me.

It’s a thick newspaper, and today there are plenty of articles: America, Iraq, the economy, the Spanish political situation – all of them subjects I haven’t paid any attention to for the last ten months because the information couldn’t get through to me. Or was it eleven months?

I don’t have a math teacher yet, but I really need one. Or maybe not. It’s horrible to go through life as an illiterate. A whole lot of interesting information passes you by. But math is something I haven’t missed very much. It’s a kind of blessed ignorance that I’ve rather enjoyed. Occasionally I called the bank and asked how much was in my account. The lady told me a number, but because it was more than four I couldn’t grasp it very well. “Then I can still buy this work of art,” I told her. She thought I was telling her a fact, but actually it was a question. She never said no.

With the help of the lady from the bank I can go through life without having to do any math. But a life without reading is boring. Nobody’s there to fill in the gaps.

Now I’m going to decide what article I’m going to read. Maybe something from the book supplement, a piece about a writer. A short piece about a writer who lost his memory. That sounds fascinating. Whether I’ll still remember it on Monday, when I have my reading lesson, is another matter. But at least I’ll have done my homework.

The bag

My brother has brought me a bag with things in it that I had left in Amsterdam. I had tried to visualize what might be inside and came up with two or three things. When I finally open the bag it's a big surprise. What beautiful shirts! The person who bought them must have had wonderful taste! My own shirt is a present for me. I'm very pleased with it and today I've put it on for the first time.

My head is a bag that I've left somewhere and that my brother is bringing me. Each time I open it I find myself looking at a bag full of surprises. Some things please me and others don't (I never would have bought them myself).

Sometimes it's nice not to know anything anymore. It makes the bag feel light. But it can also be a problem: when you travel light, you may find you need something that you don't have with you. You've got it all right, but it's somewhere else. That's the way it is with me. Besides the light bag there's also an enormous trunk, but I can't open the lock – I've lost the key. So the trunk stays shut. I'll just have to make do with the weekend bag, that endless source of surprises.

Hat rack

Aphasia is a handy hat rack that I can hang anything on, including all the negative stuff. One of them is the nausea that I've had for more than a year now. But I had that nausea before I came down with aphasia. Back then it was a side effect. There was never anything really wrong with me, it was just the medicines I was reacting to.

Nausea is a well-known side effect of the HIV inhibitors I take, all five of them. But side effects have been out of fashion for quite some time now. I don't talk about HIV anymore. Forty million people have it; it's so common. No, aphasia is a much more difficult word. Not many people have heard of it. It's more exclusive. That's why I'd rather have it.

Like a good aphasiac I'm all too eager to forget that common disorder, but that doesn't make the nausea go away. It's always there, though sometimes it's less noticeable. Getting used to something and aphasia – every cloud has a silver lining.

But every evening at about eight o'clock it gets tough. That's when there's no getting around it. I'm sick and tired and all I want to do is go to bed.

I haven't had an appetite for a long time. Sometimes I think about the time when I could eat like there was no tomorrow. There was never enough: a cow, a horse, a horse and a half and I still couldn't sleep from the hunger. Now I dread mealtimes. I never feel like eating. Except the things I never used to like. Sweet things, for example. I'm not hungry, but a slice of Sachertorte goes down as easy as pie (as long as it's from the Escriba bakery). I've become terribly critical. It really has to be the best of the best or I won't eat it. That's a bit of an excuse, actually. I'm looking for excuses for not eating, which I never did before.

What I *did* do before is no longer very clear to me. That's a

symptom of the aphasia, fortunately, not of the HIV. I think. I tend to get symptoms and side effects mixed up. That's why I'm only too eager to blame it on the aphasia these days. A handy hat rack that I can hang anything on, including all the negative stuff. Or did I already say that?

Viewmaster 6

The apartment is spacious. It has a high, white ceiling, a parquet floor and large windows with half-open Venetian blinds. The daylight casts a shadow of stripes on the blank walls, making the apartment look like a film set or stage scenery, a staged place.

Felipe asks if I like it. Everything pleases me right now: the apartment in an old-fashioned district of Mexico City, the street with the wide esplanade in the middle, the city with its millions of people who all seem to be outside at the same time, the country with the musical language and Mexico's ardently worshipped Guadalupe, the mysterious smiling virgin. Felipe pleases me most of all, with his sparkling eyes that look at me so hopefully. He's twenty-four, just like me, but he seems so much wiser; maybe it's because I haven't fully mastered Spanish yet.

Even before my lips touch his, Felipe has opened his mouth for me. I search for his tongue, stroke the roof of his mouth and feel my way along his teeth, one by one. He tastes of coffee, oranges and chili peppers; I discover a pit that got stuck between his molars and swallow it.

Later on I notice his white briefs hanging on the back of the chair. "Yaco" it says in big letters on the red elastic waistband.

Ground floor

Sometimes I can act as if there's nothing wrong, as if I'm still the same. But when it comes to climbing stairs I invariably screw up.

It's even true with stairs that aren't stairs but little steps. Two or three steps are enough to set me back, and I reach for a railing that isn't there. Someone who gets dizzy and reaches out for an invisible railing doesn't really make an entrance – he descends on the scene, even if he doesn't fall flat on the floor.

A world without levels would be ideal for me. Then I could really act as if nothing was wrong.

Tricks

If you can't be strong, be smart. And if you can't be smart, at least give people the impression that you're not stupid. It's a question of tricks. The older you are, the more tricks you have up your sleeve and the more people think you're smart.

That's the tragedy of aphasia: you lose all your tricks. People think you're stupid and clumsy because you don't have any of the tricks that other people use to hide their stupidity and clumsiness.

But life wouldn't be life if you didn't quickly come up with new tricks to disguise the absence of the old ones. I've put together a whole new collection, almost as much as I had at first, to skirt the track of obstacles that my daily life has become. It starts in the morning in the shower. Showering was so difficult, so slippery, that I had started dreading it the night before. Now I shower at the gym. There are thirty showers there with built-in shampoo and built-in soap dispensers and strong water pressure that more or less happens all by itself. If one doesn't work, there are always twenty-nine others. There's so much room that no one notices as I slide from one shower to the next.

Breakfast was another obstacle. I still can't get my own breakfast so I have breakfast at the bar on the corner by the gym. Every morning I go to the sidewalk café and order fresh juice, a glass of water and a tuna fish sandwich. I'm already a regular. They know what I eat every morning so all I have to do is show up and my breakfast appears.

It helps to have money. You can use it to buy what other people have to do themselves. Luxury hotels were invented especially for people with money. They're based on the assumption that people with money can't do anything on their own. People with money take my reality for granted. When something goes wrong, people with money are allowed to stamp their feet and rant and rave. That's what they pay for; that's

normal for people with money.

Tricks, as I said, is what it's all about.

Bread

This morning my plan was to buy bread. For the first time. Alone. I didn't sleep very well last night. I mean, anything can go wrong. Say that Ollie pulls on his leash or has to stop and poop. I clean it up, and as I do I drop the bread. Or I accidentally throw the bread in the garbage container and take Ollie's poop bag home. The most unexpected things are the things that happen. You've got to be prepared for anything.

Thrashing around in bed, I imagine what would happen if the baker didn't have any change. So in the middle of the night I started searching for coins. Then I fell into a restless sleep.

I woke up with the thought that I might buy the wrong bread. Not the bread that we eat every morning, but another kind of bread. How can I be absolutely sure that I'm taking the right bread home with me?

I decided to postpone the excursion one more day. I'll save the bread that Felipe buys for me today, keep it in the original paper and take it with me tomorrow, with just the right change. And I'll buy two loaves that are exactly the same. Then I'll know for sure that I've got the right ones. There's a practical solution to every problem.

But this morning I'm not going to buy any bread.

Angry

In the hospital I was often struck by a sudden and overwhelming sense of panic. I can't remember what the panic was all about – what it was that filled me with such anxiety. I can't even remember what it was like. All I know is that it happened. And even now I still get this vague, unpleasant feeling. It's not really a memory – more like imagining something that tastes really bad without ever having actually tried it. It's like someone else's memory, someone whom you, vicariously, can't stand. I think that's the key – that vicarious bit. I no longer really knew who I was or what was happening, so it's no wonder I panicked. That thought alone is enough to frighten the daylights out of you.

With the help of strong medicines, the whole business – me, that is – was brought under control. I'm no longer bothered by panic attacks, although I do get something that comes very close. It isn't focused on the inside, as it was in the hospital, but more on the outside. It has the same intensity as that former panic did, except this is more like anger – and there's no holding it back, not with the best will in the world. It's terrible. It's like an itchy scar, but tame in comparison with the power it could unleash.

It hits me all of a sudden, but with such regularity that I can hardly call it unexpected any more. I'm in a restaurant, I've finished eating and I've asked for the check. The check doesn't come, or at any rate it doesn't come fast enough.

And I get angry. Very angry. I become furious, raging. I stand up, grab the tablecloth and tear it in two. I grab the plates, one by one, and smash them to smithereens against the wall. Then come the glasses, and the silverware. It all leaves a brown smear on the wallpaper. I throw the ashtray at the table next to us. When the frightened people stand up and move back, I grab them by their short hairs and hurl them

against the wall. One of the personnel hurries out to save the rest of the clientèle. I grab him by the throat and squeeze so hard that I hear a quiet crack, like the sound of a brittle chicken bone. "The check!" I scream. "I asked for the check ten minutes ago!"

This is what I would like to do, but I just stare straight ahead. When I start trembling a bit too hard and feel like I'm losing control, I stand up and walk out of the restaurant. Felipe follows me, muttering excuses to the waiters and the startled onlookers. "He hasn't been himself lately. I'm so sorry," he says.

I slam the door and quickly cross the street. This is one of the few times when I don't totter. But I don't do anything else. After all, they might think there was something wrong with me.

Angry avocado

Objects, too, have shorter fuses these days. Take the avocado that I wanted to slice for breakfast this morning. Once upon a time – last year – the avocado let itself be sliced quite easily. Now it puts up a fight; it lies there in such a way that I can't get the knife in. If I say anything – come on, lie down, behave yourself – it starts acting up. It grumbles and twists and moves around, and I've even seen it fly through the air, smack, right against the wall, breaking up into little green pieces, a live guacamole.

What the avocado does in its spare time is its own business, of course, but when it starts staining my kitchen walls it means that other people suffer, other people have to clean up all that green gunk. I tried talking calmly to the avocado and explaining that there are less passionate ways of expressing yourself, but it's all a waste of time. It just won't listen. It goes its own way, through the kitchen and – thwack – all over the gleaming white tiles.

Sometimes I long for the good old days, when avocados listened to you and tiles stayed gleaming white. But those days are gone forever. Everything has changed and the avocado does what it likes.

I've decided to resign myself to the situation and not to lower myself to the level of the angry avocado. Calmness and control, those are the essential differences between a piece of fruit and a human being, between an angry piece of fruit and a grown-up human being.

Viewmaster 7

It's two o'clock in the morning and still warm. The window is open, the polluted air of Mexico City stings my throat. It's like green jalapeño peppers – they make my eyes water but I eat them all the same.

I hear the garbage truck in the distance. Felipe has mounted a cover on my big work table with a microphone, so my words can be heard in Hilversum during the morning hours. I'm broadcasting live, but I'm on hold. Before I can make my report on a leaking nuclear power plant in the state of Veracruz, I have to listen to the pedestrians and bicyclists as they take the ferry over the IJ to work on this cold Amsterdam February morning.

I've finally got what I always wanted: to be in two places at the same time, home and far away.

Sound off

Sometimes I'm forced to talk, and when I am I have to think about why I have to say anything at all. Somehow I make a connection between talking and thinking. That shows how sick I am. Only when I'm completely cured will I stop connecting the two.

For me talking is terrible, talking is torture. It's just like walking, mathematics or remembering – it's cruel. An idea doesn't show up naked. Only when it's disguised, so you scarcely recognize it as a thought, can I bear to look at it.

I want to watch with the sound off, because watching with the sound on is too much like talking. Maybe that's why I like writing so much; you can write with the sound off. When you read, the sound has to go back on, which is why I don't like reading. I never read what I write, or I read it only if I make a deal with myself to forget it right away. And then I make another deal not to forget the deal.

Recently I was in a museum. You could rent headphones there that provide you with an explanation so you can understand the paintings better. That would really help me, as a new stupid person, I thought. But the explanation was about the paintings. I turned off the sound. I kept the headphones on because I didn't want to look too conspicuous among all the other visitors. Only later did I listen to the recording – all by myself, in a dark restroom.

Image with explanation is excessive. It's confusing for types like me. That's why I prefer to go through life with the sound off. If other people listen to what I saw or write, I can't help it. I can't take their sick penchant for overkill into account. Certainly not if the problems can be solved with one push of a button.

Nirvana

In the beginning I hated it, this chaos in my head and in my life. It was a source of endless irritation; I wanted everything to be nice and neat, I wanted to straighten up the mess. But it didn't work.

Recently I've found some bright spots in this dark picture. There's a certain freedom in all the chaos. It's such a mess that I wouldn't know where to begin straightening it up, so I just let it go. I forget a great deal. In the past, part of my head was filled with all the things I couldn't risk forgetting without letting it all slip into chaos. Now that the chaos is here, there's room for other things. It's empty upstairs; it's spacious and rather bare. That gives me a feeling of fresh freedom. Organization has its own beauty, but it's a beauty that I can't achieve right now. I'll have to make do with the chaos that's here. The more I accept this, the more space there is – space for emptiness, for nothing.

Perhaps this idea of chaos has to do with the fact that I've lost the sense of time. Time is like euros. I know what it's worth if I convert it, but I can't feel it. Maybe that's why it's so difficult for me to be patient. I don't understand "later" very well, just like I don't understand "back then" either. The only thing I can comprehend is "now."

I'm like a little kid or an enlightened Buddhist, someone who's studied the essence of existence all his life. It just fell into my lap. It happened when I wasn't paying attention. Some people call it a sickness, a neurological disorder. Other people call it enlightenment. A few even regard it as nirvana.

Every so often at some unexpected moment, when there's nothing else going on, it occurs to me that this isn't really so strange after all; it's a kind of heaven. But usually it's just plain tedious. It's no fun being the sole occupant of nirvana when all my friends are just

living on planet earth. It makes me homesick. I want to be with them, off my cloud, away from nirvana. I just want to be back on earth, like everybody else.

Passive knowledge

During a dinner in Basel, a serious German gentleman asks out of politeness what I collect. I can't think of a single name and I look at my best friend Frank (because he knows everything; that's why I brought him along), but Frank is deep in conversation with a famous painter. I try thinking harder and point to the painter, understanding full well that that doesn't count, but not a single name occurs to me. I pause for a moment, then I tell the German gentleman that I've had encephalitis and that remembering is still rather difficult for me. So I tidily manage to divert the conversation, despite and mainly thanks to my encephalitis. Afterwards the artists trickle back in. "It's me again," says Jeff Wall. "Me too!" shouts Bill Viola. "And me," says Tony Oursler. Pipilotti Rist sticks out her tongue, always a sure-fire attention-getter.

I experience life as passive knowledge. I recognize most of it, but I can't come up with it on my own. It's like a language that I don't speak that I can read and understand perfectly. But my life is not a dead language; my life is alive. My passive knowledge is a tad awkward in a world that expects you to spout a bit of knowledge every now and then.

Felipe slips up sometimes. He asks me questions that I used to know the answer to. Back then I never even gave him the chance to ask questions; I spouted my knowledge left and right, I told him everything, whether he wanted to know it or not: the price of a ton of West Brent [**don't know what this is!**], the capital of Slovakia, when Charlemagne was born and what the distance is between Vienna and Berlin. I don't know that anymore, and I don't want to know it anymore, either.

Yesterday Felipe accidentally asked me the exchange rate of the Swiss franc. I gave him an angry look and he got it right away. He apologized for asking such a dumb question.

It was just like the question the doctor asked who wanted me to tell him what day it was. I don't answer such dumb questions, certainly when I don't know the answer.

Welcome home

Felipe and I are in Bangkok. It's my first big trip since I've been "better." The airport smells exactly the same, the people greet us with the same friendly laughs. The hotel driver still remembers us from the last time. We ride in the same beige Mercedes down the same highway that looks exactly the same, just like the city. We're stuck in exactly the same place in a traffic jam that lasts exactly as long as the last time.

The hotel is still in the same place, we have the same room with the same view of the same river as the last time we were here, two years ago, before I got sick. We set off to do exactly what we did the last time. We stroll down the same street to the same restaurant, where they also recognize us. Suddenly I remember how we walked from our hotel to this classic Thai restaurant the last time, telling stories about our youth. Felipe's stories took place in Mexico City, more than nine thousand kilometers from mine in Rotterdam, yet we experienced the same things: mothers who sometimes didn't seem to be there, even though they were sitting right across from us, fathers too busy with important things, brothers and sisters who played games we didn't want to play.

I order the same things I ordered the last time, that is, what I suspect I ate the last time. And suddenly I see Felipe's mother before me as she answers him by way of a song. When Felipe used to ask her things as a child, she never gave him a direct answer but sang a song instead. Then he would have to interpret whatever it was she meant. Her repertoire was endless, but Felipe never knew if he was deciphering her code the right way.

The fact that everything is exactly as it was two years ago, that the Thai still remember me – but mostly: that *I* remember it all – is a completely new experience in my present state. The fact that I can

still remember some of what Felipe and I discussed at the time gives me goose bumps of surprise and pleasure. I had to travel to Thailand to come home.

Then, on the third day, I suddenly have the urge to discover something new. During our travels before I got sick we always went exploring: Myanmar, Cambodia, Laos, Vietnam. I want to do that now – I want to go to a country that I know nothing about, a city I know nothing about.

But I don't. I'm much too sensible. What I do decide is that we'll have lunch at a unknown place. I'll ask the driver to drive along a new route and to get stuck in traffic where we've never been stuck in traffic before.

Many happy returns

Sometimes I come across notes in my date book that I made six months ago. Most of the time I can't decipher them. I look at handwriting that is no longer mine; it's childish scribbling. Sometimes I wonder whether I haven't become a bit of the child I never was. And I wonder what that means for all those poor people living around me.

What the childish handwriting mostly noted was birthdays. I read that today is Licura's birthday. But I haven't the slightest idea who Licura is or what name I was trying to write. So the person whose birthday is today won't hear from me, and won't hold it against me because I've been seriously ill.

But I haven't forgotten Licura's birthday entirely. I'm thinking about him and wondering who he is, and whether he is maybe a she. So many happy returns, Licura – whoever and wherever you are.

Viewmaster 8

The uncomfortable looking laboratory receptionist hands me an envelope, which I open when I get out on the street. It says: anti-cuerpos antigenos HIV – positivo.

Does positive mean negative? Does positive mean that in a few years I'll be dead?

I stand in the middle of that busy street in Mexico City. Cars race past me, pedestrians push me from behind, daylight begins to fade.

I calculate that if there's a 10 percent chance that the results of this test are incorrect (as the doctor told me after finally agreeing to give me a few minutes of his time), and you have a 50 percent chance of getting AIDS if you're HIV positive, then I have a 45 percent chance of being dead within two years. Or is it 47.5 percent? I've never been very good in math, and I wonder if there's any point in learning now.

Cut to pieces

“I have something for you,” says the speech therapist. She says this every time, as if she's talking about an amusing surprise, a surprise with a funny poem that'll make me howl with laughter. And every time it's a confrontation with something I can't do, which is why I have yet to howl with laughter.

This time she's cut an article into pieces, and the idea is that I'm supposed to put the pieces back in the right order. So that means that I have to read the article, which puts the speech therapist in the territory of the reading teacher. What happens when people enter places where they have no business is something we see every day on television in Baghdad. I cannot allow this, for political and mainly for moral reasons.

First I stare at the clippings from which I'm supposed to make one whole piece. As far as I'm concerned it doesn't matter what order they're in, because I'm not going to read the piece for political and moral reasons. Then I think of a cunning trick (if you can't read, be clever) and turn all the pieces over. On the back is a photograph, which I manage to put together in no time. When that's done, I turn the clippings back over and tell the speech therapist that she now has the article she so urgently wanted to read but instead cut into pieces in a fit of mischief. That floors her. It also doesn't help that I say this in Dutch, and she doesn't speak Dutch. She refuses to go to Dutch lessons – but that often happens with non-aphasiacs. They're terribly stubborn.

So I know what I have to do. Reality has been cut into pieces, and I just have to turn it over and put it together. This aphasia lesson isn't pointless at all, but whether the speech therapist has learned very much from it remains to be seen.

One year ago

Someone told me that I was admitted to the AMC on December 8, which is how I know it happened one year ago yesterday. The way I feel it could have happened two weeks ago, forty years ago, never. The way I feel, two weeks ago, forty years ago and never all happened at the same time.

“Never” is the one I want most of all.

My life has not been without its unpleasant things. “Too bad for me,” I say to myself when they come along. But I’ve learned from them. They’ve become part of myself. They belong to me, just like my nose and my eyes belong to me. I couldn’t be without them.

That’s not true with this event. Never in my life have I so wanted to wish something away. If I were given one thing to wish for, it would be that this had never happened, even though things have happened in my life that were much worse – irreversible things, things that certainly would never have been missed if they hadn’t happened at all. But I accept those things.

This is the one thing that makes me silently hope that somebody will tell me it was all a bad dream, a dream that seemed real but wasn’t. My preference is that it’s my doctor who tells me: he’s a doctor, he knows, and if he says so then it’s true.

I keep hoping it didn’t happen. Like a mother who hopes that her dead child, recently killed in a car accident, will come skipping around the corner, I keep hoping that my doctor will tell me it wasn’t real. Like that mother who is repeatedly disappointed, I’m disappointed when my doctor doesn’t deny the truth.

It surprises me that I want reality to be different from what it is. Before this happened, my most ardent wish was to be able to see reality just as it is. “If I can just see it as it is, I’ll be able to understand

it and live with it,” I used to say to myself.

Now I don’t want to see reality any more. By hiding my head in the sand I try to undo something that’s already happened.

Of course I know that you can’t undo something that already happened. Of course I know you’ve got to make the best of the things you can’t change. I know it, but I don’t want to know it, and not wanting to know it is stronger than anything else. Never in my life have I not wanted something so badly. I don’t want it so badly that it surprises even me. It leaves me speechless. Not wanting something with this much intensity is just not me; putting so much energy into something that there’s hardly any energy left for other things – it’s just not me.

I used to wonder why this is so. I analyzed it, all the while thinking that it would be much easier to live with it if I could just understand it. But I don’t want to think about it now. I don’t want to analyze, I don’t want to understand it, I only want to live. I want to live, but not under those conditions. My will to live is just as strong as my will not to understand. And that will surprises me, too. I knew what I wanted – but that I wanted it so badly, no, even I couldn’t have suspected that.

Right now I’m just going to concentrate on wanting and being surprised. I don’t have a second of time for anything else.

In a hurry

When I was fresh out of the hospital, one year ago, I had my own unique way of walking. Instead of picking one leg up and then putting it down – first the heel and then the rest of the foot, as was explained to me during physical therapy – I just fell forward, after which I would quickly heave myself back up. This meant that I didn't tumble to the ground but advanced by fits and starts. I called that walking.

The people around me held onto me with their heart in their mouth. They were afraid I'd end up flat on my face. But every time they thought I was about to take a nose dive, I disappeared. I was already doing my fall-down walk across the next canal. They could hardly keep up with me.

Not much has changed in that one year. I still jerk my way down the street. I'm in a hurry. I don't have time to take it easy, because if I do I go slamming into the pavement. Standing still is repugnant to me. I don't ponder things, either, because pondering – like remembering – is a kind of standing still, which I have to avoid at all costs. Anyway, I have no time for it.

Whenever I have to stop and wait, I'm seized by intense panic. The only way I can master that panic is to get very, very angry; when I'm fit to be tied, I out-scream my own fear. No wonder I pull so hard on Ollie's leash when he starts sniffing a tree. I want our French bulldog to be a greyhound. I want him to run, just like me.

Sleeping is hard. Sleeping is a form of standing still. It's worse than that; sleeping is lying still, and you only do that when you're dead. I've been dead long enough.

Reading takes me too long because I have to sit still when I'm reading. I like to write, since writing is running while seated.

I live hard and fast; I'm always in a hurry. It's like being afraid

something will pounce on me if I stand still. I don't know what that something is. The only way to find out would be to stand still, and I can't do that.

A wise guy would say that I'm running away from myself, but fortunately I'm not a wise guy. What I have figured out is that I'm running away from what happened. If I were to think about it, I'd be filled such intense and overwhelming retroactive terror that the sparks would fly. That's why I run, and that's why I have to move forward. That's why I write.

Naked under my skin

In some fifteenth-century paintings you see saints who are smiling benignly as they undergo torture. Well, there ain't no such thing as a free lunch. No pain, no glory. Chopped off hands and heads, nails through the body, arrows, the gridiron – the fantasy of medieval executioners was infinite and original. Each saint was given a custom-made treatment to elevate him to a loftier level.

Like my memory, my knowledge of the saints is rather poor. I've got to hit the history books to find out which saint was flayed alive – because I identify with him, or her. That is, I often feel like someone whose skin has been stripped off. Exposed blood and muscles and tissues. Naked – that's how I feel, without the sanctity. It's as if the protection that I had so carefully applied for forty-seven years had been pulled off with one firm tug. I stand here as I am, with nothing to cover myself. I feel every gust of wind, every word, every touch. It's raw and it hurts, but one thing is certain: I feel! I feel the embrace with words, I feel the bright blue of the painting in the hall that's actually a photograph, I feel the yellow and the orange of the photo that could be a painting. Made with brushstrokes or recorded with light, it doesn't matter. I'm naked under my skin and I feel everything.

Once upon a time this strong feeling I'm feeling now was tempered. Things were tucked away in various pigeonholes. It was handy, practical and wise – so I don't want to have anything to do with it anymore. I'm enjoying it, these raw feelings. They're kind of like uncooked carrots: they make a lot of noise, and chewing them isn't always a pleasant sight for those around you, but at least I can feel them. I never felt that tempered stuff.

Whenever I'm feeling too many things at the same time, I close my eyes for a minute. Then I carefully let a couple of images trickle

in: the patio in the morning light, the dog asleep in his basket, the mountain of clothes that lies waiting patiently for the new day.

Then, after a few minutes, I open my eyes, wide open. I want to see. I want to dress the nakedness under my skin with images, images that are what I am and what others are. We meet each other in those images, so it's not bare. It's naked under my skin – but never bare.

Traveling with a stranger

I went on a journey with a stranger this year. No, not someone other than Felipe. Of course not. Felipe is still the same sweet, caring and completely original man. I'm talking about a really different person: the new me.

At first I was a little nervous. You never know how this stranger is going to react, and it can get pretty embarrassing at times, especially for bystanders. So I always maintain a certain distance, hoping no one will see that we're together. He moves around like somebody who's had one too many, and like the slightly tipsy he doesn't realize what kind of impression he's making on those around him. He doesn't seem to care, at any rate. And that, of course, is the strangest thing of all: other people may die of shame, but he doesn't give a hoot.

People are always rushing in to help him – people who think that any minute he's going to topple over – and he acts as if he doesn't see them. He stumbles through the most fashionable hotels like a drunken sailor. A stewardess asked him recently if he needed any help putting his bag in the luggage rack. "Oh no, absolutely not," he said, and then he capsized, disappeared between the seats and was nowhere to be seen. Four stewardesses, the pilot and the co-pilot rushed to help him, but he insisted that nothing had happened. During the entire flight no one left his side. They wanted to avoid any worse accidents, certainly in this time of explosions and catastrophes, but none of this got through to him. He thought the service was terrific. "Only in Asia can you get service like this," he said, and he decided never to travel in any other continent.

The people in the hotel were extremely attentive, too, he found. Every thirty feet there was someone else waiting to catch him if he started lurching. He himself thought he walked perfectly straight –

another example of how the East can influence you. But the personnel complimented him on his jogging. "How nice that you practice in the corridors of the hotel," the butler said. "How sensible that you don't let yourself be restricted by the artificial limitations of a gym."

He's not much of a reader. He says it's because of the way the light falls on the page – always the wrong angle. He thinks he can write again, and that it's perfectly normal not to be able to read what he writes (he can't read, after all, because of the unsympathetic light). But nobody can decipher his handwriting. I know – I've tried. There's no difference between his handwriting and a child's drawing; there's no rhyme or reason to it.

It all goes right past him. He literally sees nothing (or he only sees what suits him). He's walking around with blinders on, and I could die of embarrassment. But he has no intention of letting himself be bothered. So I'm afraid I have no choice. I've got to follow his example and decide I couldn't care less.

It takes some getting used to – and a lot of practice. But I've got no choice. It's too complicated explaining to everyone that I'm not the person I seem to be. And it doesn't work. People look at me as if I'm soft in the head, as if he and I are one in the same.

So I guess I've got to go on living with this stranger. There's no other way.

Viewmaster 9

Felipe has found a job in the United States. I can get better medical help here than in Mexico, but otherwise there's not much to do. "Just enjoy it," my American doctor told me. Except that Felipe works from seven in the morning to late at night, and when I'm all by myself I cannot enjoy a tree in a garden bereft of all human companionship. I scratch on the bark of a beech tree, leaving a pale, bare area that startles me. I run to the garage, grab the super glue that Felipe uses to fix up furniture and glue the bark back onto the tree. From a distance you can't tell it was ever pulled away.

The front door

"Somebody tried to break in," said Felipe when I came home last night. "Look, splinters and debris." He went back to planing the door with a worried expression on his face.

"Gee," I said. And then I confessed that the door was broken because I had slammed it that afternoon in a fit of rage.

Felipe wanted to know why I had been so angry, but I didn't know. There was no immediate cause. I went to my photography class and couldn't find my notebook or my ballpoint, I was late and Ollie gave me a quizzical look.

Felipe was relieved. Luckily it hadn't been the work of a thief. But I myself was shocked by the slamming of my own door; it's bad enough when a stranger tries to get into your house, but when you yourself lay into your door it's just as unsettling.

I didn't get any sleep last night because of that door – and because of what Felipe said. "They made a mistake in the hospital. I brought one Han in and got another one back. It's like two babies who get switched. You can return the wrong baby to the hospital, but this is a harder problem to solve."

He's right. Felipe got the wrong friend back from the hospital and can't trade him in for the right one. I'm not kind any more, I'm not nice any more. Mostly I'm angry, always just angry. I get angry at the waiter in the restaurant because he dawdles over the bill, I get angry at the front door because I can't find my notebook and my pen, I get angry at Ollie because he takes too long sniffing a tree, I get angry at Felipe because eating makes me queasy and I don't understand my computer lesson.

They can fire the waiter, but the others are completely innocent.

They can't help it.

And I – can I help it? Can't I just control myself a tiny bit? But I already feel as if I'm exercising tremendous control. After all, I didn't smash the front door to smithereens, or the waiter, Ollie or Felipe. That in itself is a stunning example of self-discipline, if you ask me.

I think it's terrible that Felipe is distressed, distressed about me. That's not my intention. But I can't help it. The feeling of powerlessness that regularly overwhelms me is so strong that I can't suppress it. It's like an erection, except it's unpleasant.

Last night in bed I decided it would be better if I just had myself committed. Or worse. But I know that being committed, or worse, is much more drastic than my fit of rage. It's less easy to sweep up than the debris at the front door. I know I have to deal with this myself, but I haven't the faintest idea how to go about it.

I have only one idea. It's a resolution. Actually, it was Ollie's suggestion. Today I'm going to take him out for half an hour and try not to get angry. I'm going to spend that half hour enjoying him, the way I used to. I'm going to practice it today until I succeed. All the other things are unimportant. I'll drop out of the photography class. I don't have enough time for it anyway. First I have to take Ollie out and learn to enjoy it.

First that, and then it's Felipe's turn.

Morning walk

My life a full plate, and the only way not to make too much of a mess is to divide it into bite-sized bits. In the hope that it won't get stuck in my throat I cut it up into tiny little pieces. I keep thinking it's easy to swallow, but then I have another coughing fit and out it comes; the pieces are never small enough. Tiny little is still too big for me, and that makes me angry.

Ollie is a big help. Yesterday he came up with the idea of going for a walk without quarreling. I thought that was asking quite a lot – it would mean not being angry for at least twenty minutes. But we tried it. The first three minutes were fantastic. I enjoyed the early morning; I saw a golden leaf in a puddle of water and looked forward to the chocolate curls I was going to buy at the Escriba bakery.

On the way we passed two girls. "That one looks good," said one girl to the other.

"What do you mean, the dog or the guy?"

"Both, of course," she said, and they started laughing.

I beamed. It doesn't matter whether it's true or not. It was kindly meant, and that's all the counts.

Ollie smelled something interesting near a tree and starting pulling. I gave the leash a tug and Ollie turned around.

"I thought we had agreed that we weren't going to quarrel. It was going to be fun, and we were going to enjoy everything we came across along the way: golden leaves in puddles, Colombian whores looking for their last customer – that kind of thing."

"Two customers, you mean."

I gave the leash another tug.

On the way back Ollie peed against every tree, smelled every plastic bag and sniffed every lamppost. At the twelfth lamppost I

couldn't hold back any more and I gave the leash an enormous tug. Ollie flew through the air. He didn't say anything. He just looked at me, and that was more than enough. I turned my head in shame.

Later we'll try it again: walking for twenty minutes without getting angry. I'll see if I can make it this time.

Forty euros

Felipe finds two twenty-euro notes in the pants I gave him this morning because they're three sizes too big.

"Forty euros! How great! I know exactly where that comes from," he says while folding the bills up carefully. And he starts telling me that the forty euros is the first money I got from the ATM when I was just beginning to walk again. I went out alone on the street, tottering, spinning and dizzy. Actually he didn't want me to go, but he had decided it was better if I were to practice being independent again. He had written down my PIN code in big numbers and let me go with his heart in his mouth. Would I ever come back?

I did come back, after a rather long time, because I hadn't been able to find the street corner. I lost the money along the way, as I lost most things back then – money, keys, my PIN code, my memories, the way.

This story makes me cry. I cry easily these days. The ladies from the Aphasia Society explained to me that this often happens with people who've had something go wrong with their brains. We cry at the least little thing. We cry when we're happy, we cry when we're sad, and we cry when we're angry. We're angry a lot – that's common behavior, too, and it comes from the powerlessness we feel, the ladies from the Aphasia Society explained to me.

Now I'm sad, happy and angry at the same time, so I cry in triplicate. The worst thing about it all for me is when other people worry, when Felipe worries, when my family and my friends worry. They were worried and I wasn't there to reassure them.

And that's another reason to burst into tears.

Little Children

I want Felipe with me all the time. The only way I feel safe is with him. I hang onto him like a toddler clings to his mother. When he goes to the kitchen to get me some soup and an apple, I follow right behind him. When he takes Ollie out I stand on the balcony, waiting until he comes back. When he goes shopping I walk along, and I sit on a bench with Ollie, waiting until he comes out of the store. It's terrible for me that recently – for the first time since I got sick – he's gone back to his workshop to restore antique furniture.

At the same time I want to put it all behind me, everything that happened a year ago in which he was so closely involved. I've got to get away from the past as quickly as possible, the way you flee from the place where you witnessed a terrible traffic accident, afraid that the pulverized cars are going to ride over you again. I've got to enter the world in which I don't hang on Felipe, in which I can stand on my own two feet. That's why I decided a month ago to buy a special work of art.

Felipe asked me whether I was really up to getting back into this sort of thing. There are so many people without scruples. Wouldn't it be wiser to wait a bit? No way was I going to wait, so I promptly sold my choice securities and bought the most expensive work I've ever acquired. In the gallery, when I sealed the deal with a handshake, a wave of warmth washed over me. For the first time in twelve months I didn't have the feeling that I was tottering. I felt strong. It was that handshake had pulled me up. But Felipe was angry, angry and shocked.

Now the nine light boxes by Jeff Wall are hanging in a museum in France. I went there last week. Visitors admired the work, pointed to the faces of the children and the colorful sky forming the background. But when I myself looked at *Little Children* I mainly saw Felipe's

anxious face, his despairing eyes. I grabbed his hand, and for just a moment I felt the same strength I had felt a month before. Then we walked on. We had to go further.

Anticipation

Yesterday morning I decided we had to go to Bali. Immediately. Right away. At the moment I was on the treadmill, and if I had had my druthers I would have gone straight from the gym to the airport, with my wet training shorts and T-shirt under my arm.

I got angry when the young woman at the travel agency said she's need a little time to arrange a few things, so I decided to book the trip with the agency that could respond to my impulses immediately. Within three days we would go to Bali. It was all settled.

A little while later doubt set in. Was this wise? And is it wise to be wise? There's something to be said for giving in to impulses, of course, and for the immediate pleasure this gives you. On the other hand, the big advantage of being wise is that you have more time to enjoy the anticipation. And anticipation is also a form of immediate pleasure. You can dig into the anticipation right away, right here.

Felipe was not happy. That very week he had been given a job to restore a cabinet, and this was definitely not a good time for him to go away again. Finally I decided to postpone our trip a bit so Felipe could finish his cabinet and so I could make the most of the anticipation. That's why I'm spending the day today changing everything I organized yesterday.

It's all a little tedious. Non-thinking always involved extra work. I see it more as the aftermath of my sickness. Two weeks ago I was still feeling queasy every night. And every morning. That's over now. Now I have to sweep up the mess that my impulses have caused. It smells better.

I hope other people aren't bothered too much by the fragrance of my impulses. If they are, I offer my apologies in advance. Soon this side effect will be over, too. Then I'll be back to my old self: wise, tranquil,

think-first-act-later.

Was I ever like that? Look, I don't even know anymore. And let's hope that *that* not knowing stays that way.

Funeral on Bali

We're going to Bali to bury all the after-effects of my sickness and to draw the recovery period to a close. I want to be better, and once I cover over the last symptoms and memories with sand they won't ever be able to find me again.

We went to Bali once before, thirteen years ago. Or was it two? I've got a photo somewhere in which Felipe has his arm around me and is pointing to something that is making us both laugh out loud. Is it a photo, or a picture that lingers on by accident, a memory?

I was deeply impressed by the funeral during that last trip. They're not gloomy events on Bali. I didn't see any mourning clothes or long faces under the Indonesian sun. Funerals on Bali are colorful parades with lots of music, lively processions of chattering people bearing sacrifices for the gods and tasty snacks for the other guests. A funeral on Bali is fun; that's the kind of funeral I want for my nightmare.

On Bali the spirits of the deceased live on. They come back to earth with a certain regularity, where they're treated with respect because they still wield influence. The dead still get to keep plenty of fingers in the pie in Bali. I'm not sure that I would want to take over the work of all those dead fingers, but my nightmare's spirit will certainly come to visit me every now and then and I want to treat it with the proper courtesy. It has a right to a certain amount of respect; it happened, after all. But it has to have a place where it can take a rest and not get into too much mischief when it goes haunting.

I'm not sure how to go about burying the spirit of my nightmare. That's why I'm going to Bali. I've got to look around all over the island, especially at funerals, to absorb the customs and rituals so I know what to do when I get home.

But you never know, maybe it's safer to cremate my nightmare right there on Bali in some remote spot. I'll bury the ashes on the beach and cover the grave with a batik cloth – or maybe I'll build a ritual platform like I've seen other people there do.

I don't quite remember how they did it, and that's why I'm going to Bali. I'm going to learn how to bury things.

Dumb

I used to think there wasn't anything dumber than people who didn't know what kind of medicine they were taking. Not only is it dumb but it's dangerous, too, not to know what you're popping into your own mouth. What if something were to happen? Felipe and I used to laugh at people who could only say they were taking blue pills or yellow pills. I wrote little pieces in which I made fun of such people. Dumb as dirt.

Now I myself have become one of those dumb people. Only my doctor knows what I take – and Felipe. He's now responsible for keeping my life alive.

Here on Bali I want to take the time to figure out what five medicines I take. We've set aside two weeks aside for this project, so there's no rush. I've reserved a special suite at the Four Seasons Hotel, because you need plenty of room to memorize so much all at once. At first I thought the bare minimum would be a penthouse with a balcony and built-in swimming pool, but that seems not to be the case, unfortunately.

It's been three days and so far I've learned the name of one pill. I can't remember it all the time, you understand – just every now and then. After another couple of days I'll know more. But I'll have to rattle them off very quickly and in exactly the same sequence. Once I've learned all five, Felipe will want me to point to each pill and tell him what it is. But that wasn't the agreement; that's cheating. I couldn't pin a name to a pill if you paid me a million dollars. I can only learn them by heart, the way I learned the Hogezaand-Sappermeer Stadskanaal by heart, but if I were dropped in the middle of Hogezaand I still wouldn't recognize the place.

Felipe is unrelenting. Every day we practice together. Sometimes he holds my hand, the way you help a child cross a busy street – a street

full of lost words.

After ten days I know the names of the pills and what they look like. There's no relaxing on this vacation, that's for sure. And in the evening, or if I haven't practiced for awhile, the names all slip my mind. Then I ask for the blue pills and the white ones, and I tell Felipe to make sure he doesn't forget the yellow and orange ones because they're fantastic. They're especially good for my memory.

The right button

We're having lunch in the coffee shop of the Four Seasons Hotel. I sit down in the lounge and pick up my camera. Suddenly I turn to Felipe with a start, the way I always do these days when something startles me – that that's very often.

“Felipe, I don't know how this camera works any more. What am I supposed to do?” I don't speak the words, but cry them.

Felipe looks at the camera. “I wouldn't know. Just use it. It'll all come back to you.”

Yes, maybe it would all come back to him. But he's so much more technical than I am, and he hasn't had encephalitis, either. I hurl the camera angrily into the corner.

But we set off, and every now and then I push a button, then another. Occasionally I turn something. That night we look at the results. The photos are strange: not ugly, but strange. There's movement in them, speed – especially in the photos of the thousand-year-old statues.

It takes me a while, but finally I understand why. I'm trembling. I always tremble. It isn't the trembling and shaking that I had several months ago. It isn't the endless earthquake from back then, but it's not entirely calm, either. There's always a little shaking, like the beginning of Parkinson's, or like someone who feels extremely uncomfortable, as if he's paying a visit to himself.

I refuse to let this stupid trembling get me down. I take the camera firmly in my hands, which causes such fierce shaking that the camera, bag and I all fall down together. “Oh, no,” I say to myself as I try to relax. “Go with the flow.” This has the same effect – I fall down. So I scramble back up, and the camera keeps ending up in various corners of the room. Then I start again. I just do it and wait to see

what happens. I have no choice.

The advantage of a digital camera is that if a shot doesn't work you can erase it right away. It takes a little while before I figure out which button to push, and after that it's the button I use the most. But after a few days I come to the conclusion that images are less complicated than words. You don't lose them as easily and sometimes they're less confusing

But I'm still looking for the button that will let you record what you see without shivering.

Clouds of smoke

I wanted to go to Bali to bury my nightmare. What I didn't realize is that the funeral had already started. Even before I get off the plane there are clouds of smoke issuing from my nostrils. The Singapore Airlines stewardess comes running with bottles of mineral water. "No, not fizzy, and certainly not cold," I seethe. But no matter how many bottles of room temperature Evian she pours over me, the clouds keep steaming from my nostrils.

Once on Bali we drive from the airport straight to the funeral ceremony. That's not easy because we arrive late in the evening and the ceremonies are at twelve in the afternoon, when the stars are favorable. The stars are invisible at noon the stars, but they're favorable.

I see smoldering sacrifices, charred papier maché oxen, and I watch family members poke through the ashes in search of bones and lost spirits – but my nightmare is nowhere to be seen.

I decide to approach it a different way and suggest that we go to the little river where we saw Balinese bathing thirteen years ago. They came walking along with towels over their shoulders and cakes of soap in their hands.

We get to the place near the little river but there's a Dunking Donuts there now, next to a Kentucky Fried Chicken and surrounded by three supermarkets with authentic Balinese art and twenty-three shops where they sell wooden figures made with the latest machinery. Almost all the shops are closed because there are no tourists on Bali. They're staying away out of fear of bombs and smoke coming from the nostrils of certain tourists.

"I can't bury my nightmare here!" I scream at Felipe, and I start stamping my foot. This turns out to be part of the ceremony, because before I know it a whole village is gathered around me, expressing the

desire to help me with my funeral for a small fee. I can get married, too, if I prefer, but it's more expensive. That's because marriage is more in demand, even now that there aren't any tourists.

I stamp my foot. Not only because I can't get rid of my nightmare but mainly because I suddenly remember what it was like here thirteen years ago. I, who thinks he can't remember anything anymore, suddenly remember what kind of soap the Balinese used back then: cakes of pink and light green Lux. I see the flowers again that the Balinese boys wore behind their ears, on the right if they were married, on the left if they were still free. I suddenly remember a little old woman who smiled before taking off her sarong and gliding into the water.

I'm angry because the past is contaminating the present. That's a malady of the non-aphasiacs, isn't it – something I haven't been troubled by for a year now?

I'm angry because the spirit of my nightmare is gone, just when I wanted to give it a genuine Balinese funeral.

So am I back to who I used to be? There's smoke coming out of my nostrils; that's new. I'm holding onto that smoke for eight days. I'll spend eight days snorting because things aren't what they were. I'll spend eight days ranting like a non-aphasiac about what I can't bury because some of the ashes are gone.

Then we'll take the plane to Kuala Lumpur, where I'll fling my nightmare from the highest floor of the tallest tower in the world.

Viewmaster 10

I'm walking behind my brother Victor's bier. He died at age 31 of the same virus that I'm still successfully fighting against. Even now I still can't help imagining that I'm here at the same time, lying on that bier. I feel the lid weighing down on me, I smell the suffocating air and rock gently to the rhythm of the pallbearers with their black top hats. In panic I turn and cling to Felipe. He gently strokes my head, and gradually it dawns on me: being in one place is hard enough, let alone in two places at once.

L'Amour l'après-midi

Today Felipe and I made love for the first time in more than a year. He had already tried a couple of times before, but I wasn't ready. Not only had I lost the knack, but I didn't want to pick it up again – such intimacy was fine for the person I was before I was sick, not the stranger I had become.

But today, during the siesta, when I thought he was fast asleep and my eyes were closed as well, Felipe turned over and threw his arms around me – not to carry me or comfort me this time, but to press himself against me. I felt his body against mine, and suddenly I was able to decipher the braille that was written on his skin. It was like one of those lost words whose meaning I had recovered at some unexpected moment. I was reclaiming something that had been stolen from me and I trembled – not from impotence this time but with the joy of reunion. Once we got started, with his mouth on mine and his hands in all the right places, it came back all by itself. It was easier than learning to walk again, but maybe that was because I was lying down and didn't have to be afraid of falling over.

When we were finished and lay panting side by side, I turned Felipe's face toward me and looked him straight in the eyes. Finally, after more than a year, I had come home.

Virgin

“This cake is so delicious,” I say to myself as I make my way through the Sachertorte that I eat every afternoon at Escriba, the bakery on the corner. “I’ve never eaten cake as good as this. Even the chocolate curl is great!” I shout with my mouth full to Christian Escriba. He’s known this for a long time, but he loves to hear me say it, every day, at ten past five.

Because my memory isn’t what it used to be, it’s as if I’m experiencing everything for the first time. A plate of salad – wonder how that tastes? Sex – wonder what that’s like? Turns out I find both of them delightful, surprisingly delightful, especially when the dressing’s good. Fresh lettuce leaves with a little oil and vinegar, some salt and pepper and a few pine nuts – nothing like it. The same goes for sex. That’s also a question of pure ingredients. Not too much and not too complicated, to really bring out the flavor.

Not too many people get the chance to do something for the first time twice in their lives. It happens to me every day. When I start out on my morning walk with Ollie, which I’ve been doing every morning for the past fifteen years, I ask myself: what’s it going to be like today? And every morning I’m surprised when he pulls on the leash. Every morning I enjoy the trees on the Gran Via as if I were seeing them for the first time, and every morning I fill my lungs with air – as if I were doing it for the first time.

Every day I relish my chocolate cake as if I’d never tasted anything so delicious in my life, every morning I enjoy the colors of Paul Smith and Bernard Frize. I’ve never been in a plane before, and I squeeze the arm

rest whenever we sweep into the sky. “I’m a virgin!” I shout, with the chocolate still on my lips as we slice through the clouds. A virgin for life, a virgin forever, every day for the very first time.

Really fake

I'm looking at the photograph by Edwin Zwakman that I bought this week. It contains a breakfast table in an apartment in a new housing development. The table is covered with a blue-and-white checked cloth; a knife lies across one of the three plates; a crumpled napkin gives the impression that the inhabitants had to rush from the table to catch their bus – in their haste one of them left behind a sandwich wrapped in a plastic bag.

The morning sun casts a soft glow on the pack of rusks, the chocolate sprinkles and the orange juice; the apricot jam in the glass jar is almost transparent. On the window sill there are plants and a cactus shaped like a rabbit, an earthenware dove and a cat, also earthenware, and a glass ashtray. You can see the reflection of the living room in the window, and if you look carefully you can just make out the contours of the photographer.

The warm light, the orange doors with portholes in the houses opposite the apartment, the lace curtains, the chocolate sprinkles – it all makes the photograph so Dutch, so very Dutch.

But the breakfast table isn't a real breakfast table, the apartment isn't a real apartment; everything is staged. The living room and the walk-through dwellings opposite are a model, the light comes from a lamp, and everything that's big is, in reality, small. Zwakman's photograph is not what it seems; what's real is fake.

Zwakman is mixing things up. I did that, too, when I lay in the hospital sixteen months ago. Every day a psychiatrist came to my bedside to ask me what season it was. It was snowing outside and there was a Christmas decoration on my nightstand, but I had no idea what month it was. I told the psychiatrist I didn't answer such stupid questions and I saw the doubt in his eyes. He was wondering whether

I really didn't know or whether I was just refusing to say. It was quite a project, trying to obscure the truth by giving the impression that I was revealing it.

That's just what attracts me about art: unwavering obscurity, confusion. You don't know what it is you're looking at, or you think you know but it's really something else. The psychiatrist thought I was in the hospital because there was something wrong with my brain. What he didn't realize was that he was witnessing a performance; he didn't know that what was real was fake; he didn't know that I was imitating Zwakman. I didn't know it myself.

My work of art cost considerably more than Zwakman's. Whether the value will increase with the passing of time is something I don't know. In Zwakman's case I have no doubt, no doubt at all.

Without glasses

But if you've forgotten everything, people ask me, if you really don't remember anything from the past, how come you can recognize all those works of art – from a distance, with your glasses off? How about a little explanation, people ask me.

I don't know. I mean I don't know anything. I can only guess. I know there are some people who can no longer utter a single word, but they remember the words and melodies from every song they've ever heard. These are people who can't talk or write, but they can sing like the best of them. That part of their brains has not been affected.

Maybe the same thing happened to me. All the parts of my brains are affected except the modern art part – that has remained unscathed. But it's not the same as it was. I still think the same things are beautiful, but now I think they're even more beautiful than before. I still like the same artists, but now I think they're even better. The fact that I once bought something by Roni Horn and Bill Viola I regard as a stroke of genius on my part.

This is the only thing I can still appreciate, more or less, about who I once was. I haven't the slightest idea what it was like – or what I was like. I can read my own pieces over again, but reading is hard. There's a lot I don't understand. Right now my own writing is too complicated for me. But works of art are different. I look at them and think, that's magnificent. It touches my soul the way our dog Ollie does when he looks at me.

There are other bits of my brain that haven't been affected, either. I still love the same people. Except now I love them much more. I've lost a lot, but what's left over has increased in intensity. It's the flip side of my fits of anger. I never thought I could get so angry about nothing. I never thought I could love people so much – so that I get

tears in my eyes when I stand on the balcony and see Felipe in the distance as he comes walking home.

What's left over is exactly like modern art; a great deal has been omitted, but what's there is intensely present. Maybe that's why I can recognize works of art, from a distance, with my glasses off.

Memory

“We’re going to play a new game,” said the speech therapist from the Aphasia Society yesterday. Because aphasiacs sometimes forget things, she thinks we’ve become children who can only be appeased with games. She wants all of life to be a game, even though we’ve just figured out that life is no game – at least not a game we can play.

At any rate, she had five memory games for me, one for each kind of memory. I no longer remember what games they were so I don’t remember what the five kinds of memory are. All I know is that most of those memories aren’t working doing their best in my case.

The game we began with, and never moved beyond (as far as I can remember), involved the speech therapist reading fifteen words out loud that I then had to repeat. Nose, garden, father, color and eleven more. After she’d read the list I could only remember one word: father. The speech therapist read the list once again. Father, color, nose. After a third time I knew coffee, geranium and radio, although the last word wasn’t on the list. By the fourth and fifth time I knew seven words, but none of the seven that I remembered the fifth time were among the words that I had listed the fourth time. So I do know all the words, but not all at the same time. Apparently they’re beyond counting.

I disagree one hundred percent with the rules of this game. I don’t agree with the rules of any game. In fact, I’m against rules in general. It really annoys me that I can’t say fifteen stupid words in sequence. It’s normal to forget one or two – but more than half just enrages me. I told the speech therapist that it was because the words didn’t have anything to do with each other. “What does nose have to do with garden?” I shouted angrily. “There’s no story in it. You can’t come up with any memory tricks to hold onto, and these days if I don’t have anything to hold onto I end up flat on my face.”

She said that’s what it was all about – that there was no connection and that I had to remember it anyway.

Why should I remember things that aren’t connected? I’d just as soon forget.

They do their best, these non-aphasiacs, but they can’t really understand you. Here at the Aphasia Society they’re pretty patient, but in real life it’s different. In real life people don’t have very much time. Sometimes they think we’re dumb, and often they find us annoying. I find myself annoying – the problem is that there hasn’t been any other Han available for such a long time that I have to make do with myself.

But I’ll have my revenge. I’m going to let the speech therapist haul out the same idiotic list of fifteen words during the next session. Then I’m going to make up a long story that contains every one of those fifteen words. And I’m going to make her repeat the story. She going to have to use all fifteen words, and I’m going to keep practicing with her until she knows all fifteen. And woe betide her if she forgets a single word.

Emergency exit

Since the evil winter of 2001-2002 my past doesn't exist anymore, and I'm not yet ready for the future. Living in the now has does have its advantages. Many Eastern philosophers and noted psychiatrists recommend it. It's hard going for Westerners, though. Usually the now is all squeezed in between the past the future; there's not much room left for the now.

For me it's a luxury to wallow so thoroughly in the now. The annoying part comes when the past suddenly catches you unawares. That happened last week. I had an appointment with my doctor in the AMC. We were supposed to discuss my financial support of a program for AIDS research. There wasn't anything medical about it, so I had nothing to fear. I hadn't even made the connection between my body and the AMC that day. All that existed was the connection between the AMC and my wallet.

But my body had its own unique way of responding to the situation. I didn't notice it until it was too late, when I entered the hospital. Suddenly my body decided it had had enough.

"Nonsense. We've got business to attend to here," I said severely.

"No," protested my body, "I'm only going if we stay close to the emergency exit, so I can escape if they try to keep me here."

"They don't want to keep you. That's not what you've come for."

But it didn't help. First my body acted as if it had never been to the AMC before. It didn't even remember the way, and it asked the lady at the reception desk how to get to Dr. Lange's office – the office it's been to fifty times before.

We got lost twelve times. I asked for directions at every corner but didn't listen to the explanation. I got very angry with myself. How could I be so stupid as to make an appointment in the hospital, of all

places? You're just asking for it!

I crept past the emergency exist, stuck close to the doors and gave myself a good talking to: you haven't come here for yourself, you've come here for the money. But I didn't manage to convince myself. Whenever I saw someone in a white coat I went for a nose dive; my heart started pounding with every stethoscope that came into view.

My doctor wasn't wearing a white coat, thank God. He was dressed like a normal person. That made me feel confident that my disguise as a healthy visitor was working, and that everyone would fall for it.

Then I remembered how I used to take our dog to the vet years ago just for the fun of it, so he gradually forgot that he absolutely didn't want to be there. He lost his fear. What I have to do, then, is to keep going to the AMC just for the fun of it, to bury the unpleasant experiences with fun.

So I'm going back tomorrow. And the day after tomorrow, and the day after that. I'm going so often that I won't know that I really don't want to go to the AMC. I'm going there to bury the unpleasant past under the happy now.

Viewmaster 11

I'm stretched out on the couch on our terrace in Barcelona, looking out to sea. The phone rings. It's my doctor in the Netherlands. He has "less good" news: my T-4s have dropped again. It's time to change medicines. Over the past ten years my virus has developed resistance to the medicines that are now available, but my doctor knows about an American trial involving the very newest medicine. He's already sent my particulars to the United States, but I have to have to go to Washington myself to have my blood tested, preferably as soon as possible.

I don't go back to the soft couch. Instead I stand at the railing of the terrace and look out over the Mediterranean Sea, which up until quite recently looked so endless and where the horizon shifted imperceptibly into clear blue sky. Suddenly now there's a sharp black delineating line. I clamp my hands around the rails so hard that my fingers start hurting. Then I go inside to pack my bags.

Party

Yesterday there was another Aphasia Society party. A couple of times a year, they – we – organize a get-together, a lunch or a kind of cocktail thing. This time it was a fall cocktail thing with snacks and drinks.

I was the only one not drinking Catalan champagne. All the other aphasiacs had glasses that were constantly full. You can't see any difference between a sober aphasiac and a drunk one. An aphasiac wiggles and wobbles, gets words mixed up, repeats himself, gives you a groggy look and sinks into a chair. And that's when he hasn't had a drop of alcohol. After five glasses of cava he does exactly the same thing.

I came home in the very best of spirits. I was in good spirits because most of the party-goers are much worse off than I am. A large number of them can, after five years of intensive therapy, say three words and use two fingers. A large number of them are totally satisfied with that enormous progress.

I was also in the very best of spirits because I can talk aphasiac to aphasiac.

"What's it like being an aphasiac?"

"It's like ..." And then the other aphasiac sits down because he knows it's going to take five minutes for him to come up with the right word. Usually he never gets to the right word, but he doesn't have to: I know exactly what he means. Shitty is the right word. It's downright shitty. But it's a lot better than it used to be.

I was in the best of spirits because the other aphasiacs also have trouble reading and don't understand what most movies are about, either. I'm a paragon of insight and balance compared with a number of the aphasiacs I tried to talk to yesterday. Every now and then I want to voice my outrage by shouting that I still feel so dizzy after a year

and a half, but there are aphasiacs who have trouble taking three steps seven years after a heart attack.

I'm in the best of spirits because we all say the same thing: how is it possible that one minute we're fine and the next minute our entire life is a mess, as if an earthquake has taken place. Our lives have collapsed, and the lives of most of the people around us. We shake our heads, because we still can't believe it – after all those months, after all those years, we still can't believe that this really happened to us.

Maybe we wouldn't feel so dizzy if we started believing that this really did happen to us. Maybe we'd be able to walk a little bit straighter. This is reality and we've got to make the best of it.

Bit by bit

I bought a book. It's not the first book I acquired during the past nineteen months. I did buy another book, but that was for reading lessons. That was required, so it doesn't count. This time I just went out and bought a book.

The fact that I just went out and bought a book is extraordinary, but how I found out that the book existed is even more extraordinary. I read it in the newspaper, this morning. I didn't read the whole article (it was more than four lines long), but I did read that there was a book out with interviews of writers. *Confesionario* it's called, but of course I had long forgotten that by the time I walked into the bookshop. I asked for "that book about writers with photos scattered through it," and the bookseller produced it as if by magic. He's either clairvoyant or he has experience with aphasiacs.

I don't know whether I'm going to read the book or not, but that's not the point. As far as that's concerned it wouldn't be any different than the hundreds of other books on the shelves that I bought out of solidarity with the writers. These are gestures of good intention, and like most good intentions they only have symbolic value.

Every time I read something I get the feeling that I don't entirely understand it. But I have the same feeling with everything. I do, I act – but I still can't really comprehend it. I understand a sentence, an image can appeal to me, but the thing as a whole – the consistency that others appear to see – is beyond me. I see bit by bit, and that's more than enough for me. What's the use of consistency? What good does it do? Give me a beautiful word, a catchy sentence, something short and succinct that I can get my head around.

I look at the words and sentences as if they're photos from a fashion magazine or an art publication. And even when I look at photos,

I mainly see the bits: a button here, a sock there, the line of an image, the color of the background. I don't know what it's about and I distrust anyone who says they do, because – like other stupid people – I have little trust in what I don't understand.

So I bought a book, and I hope it contains a couple of beautiful sentences, a beautiful word here and there. If I find them, I'll read them twenty times and enjoy them. I get pleasure from a book. That's new. I think. Because the same is true in this case: I don't really remember.

Scratching

I hurl the book by Sándor Márai across the room. "I don't want to read!"

"But you *can* read, so why *won't* you?" shouts the speech therapist.

"How should I know? You're the expert."

"Then let's try something else." The speech therapist takes out a thin book, a Golden Book with pictures of ducks in a pond. "Read this. Loud and clear."

It's a book about how important it is that others call you by the right name if you're a duck. The words don't get in the way here. I enjoy the drawings.

I ask whether the speech therapist has more of these duck books and plunk myself down on the novel by Sándor Márai.

There are twelve more Golden Books, books about ducks and puppies and pussy cats and bears and cows and calves – and tomorrow I'm going to read them all. Books for children up to age five are right down my alley. Anything more difficult is beyond me. Sándor Márai gives me a pain in the butt.

Why do I want something that I don't really want? Is it a sense that I'm missing something? Is it because it feels like there's a party going on outside, but I can't see anything because the windows of my room are all steamed up?

I wipe the windows with my sleeve. I try to figure out what I'm seeing, but the glass clouds over right away and all I can see are moving spots and stripes.

Maybe it's like my muscles. I have to exercise them, too, to make them strong again. I used to have muscular thighs. Now I have no thighs. I hover over my knees; I hang in the air. The physical therapist says my thighs will come back if I practice a lot. They're coming back,

because they're still here.

It reminds me of those lotteries where you have to scratch off a layer from a little piece of paper to see if you've got the winning combination. I have to scratch to see if I'm getting my muscles back. I have to scratch to get my words back, my sense.

Tomorrow I'm going to buy a new lottery ticket. I'm starting with books about ducks and going on to puppies and pussy cats and bears and cows and calves, till I end up with Sándor Márai. The passion for Sándor is in there somewhere, I'm sure of it. It's just a question of scratching the right place.

Getting attention

Yesterday I had a visit from a fellow aphasiac. We talked about aphasiacity.

"You can talk and you can walk. There's nothing wrong with you. You just want attention." It took my fellow aphasiac three and a half hours to say that.

"But if I wrap up that attention-getting nice and pretty, if I find an original form for it, does it count?"

"You don't count."

"That's true. I have problems with counting. I can't get any further than four."

Then we went to have coffee at the bakery on the corner, because I still can't make coffee.

It continues to eat at me, though. I finally found an identity for myself and I'm not allowed to use it: I'm a fake aphasiac. That's the problem with my life. I'm in between everything and I don't fit anywhere.

My fellow aphasiac told me he had a car accident thirteen years ago. I couldn't talk for a long time and could only get around in a wheelchair. He's only been able to talk and walk for the last two years.

"Do you get angry sometimes?" I ask him. "So angry that you can't go anywhere in public?"

"I never get angry."

"And do you ever forget things?"

"I never forget."

"I forget almost everything," I mutter, but of course I forgot what I always forget.

In the meantime I'm stuck between a rock and the hard place. My fellow aphasiac thinks I'm too good to go through life as an

aphasiac. My fellow writers think I'm not good enough as a writer. My first book ended up in the remaindered bin at the local bookshop, my second and third books haven't even been published yet. My fellow journalists never thought I was a real journalist, and I don't think I have a lot in common with other gay men, HIV positives and Dutch ex patriates. The only person who thinks I belong is the lady from the bank. She called me yesterday to tell me they're opening a special office for stinking rich people, and I've been invited. But that's a club you don't have to do anything to get into, and that's too easy for me.

I'm looking for a club where I fit in completely, and I'm afraid that's a club with only one member: me. I have a feeling there are lots of those me-clubs: six billion at the last count. But I may be wrong, though, because I never get beyond four.

Pain

Felipe is out on the balcony, oiling the teak chairs. I'm standing in the doorway.

"What was it really like, when the thing that happened happened?" Mexicans never discuss terrible things by name out of fear that they might happen all over again. It's how they bamboozle the higher powers in charge, while the clever listener gets it right away. After twenty-five years I've got it down pat. "What was it like exactly, back then?"

Felipe puts the brush on the arm of the chair, stares into the distance and says, "Your father sat beside your bed every day. You didn't say anything. Neither did he."

I can see my father again sitting beside my bed in the semi-darkness, a big man who feels small in the dim room. He's reading the newspaper, and every now and then he looks over to see if I may have given some sign of recognition.

Suddenly my stomach tightens up. I don't want to allow this picture to take shape in my head. The retroactive pain I feel towards the worry and sadness of my father, Lisette and especially Felipe is still so raw that I can hardly take it in. It's as if I had stuck a knife in their backs while sleepwalking. You can't blame me. I couldn't help it. But even so, I was the one who cause the wound. Every time someone starts talking about it I feel the scab being torn away, from their wound and from mine.

The worst part of it is that we can't share this pain. It's not the way it used to be, when Felipe and I could lay for hours in bed with our arms around each other. There are no more moments when we get lost in each other's gaze and then interrupt it with an unexpected wink. Now when Felipe and I look at each other I avert my eyes. Shame, guilt,

pity, helplessness – it all runs together. I want to comfort him. I want to make it all better. But I can't. I'm no longer the one who comforts and makes better. The fear that I will no longer be that person makes me freeze.

“You sure that's the right oil to use on these chairs?”

Felipe looks at me in surprise and nods.

I turn around and go back inside. I tried. I thought I could do it, thought I could know what really happened. But it was too much for me. I still haven't mastered the pain.

The most beautiful in the world

Yesterday I went to the neurologist. I was carrying my brains under my arm so he could take a look at them.

He responded with immediate enthusiasm. “What a beautiful set of brains you have,” he said. “And you know what I think is most beautiful? There's no sign of the big bad winter you went through. Most people still have a trace – a spot or a frozen bit or a hardened block of ice – but in your case there's absolutely nothing.”

The doctor kept staring at what wasn't there.

There were still a few things I wanted to tell him. I told him that I was doing better than several months ago, and that I had so many plans and ideas that it sometimes it made me a little dizzy. I told him that I wanted to carry out all those plans and ideas because I have no time to lose – I have to make up for those two lost years. “I'm in a hurry,” I shouted, tugging on the lapels of his white doctor's coat. “I'm in an incredible hurry, doctor. That's why I've come to you.”

I think I really wanted to say something else to him, but in view of his enthusiasm for my beautiful brains I figured this was a better idea.

The neurologist couldn't take his eyes off my MRI scan, however. He hadn't seen such a gorgeous set of brains in a very long time. It was a real treat. “You're sure you don't have a copy of this scan somewhere? I like to look at it, you see.” He blushed slightly.

“Don't worry,” I said. “I just had 35,000 copies made. I'm going to mount them on every lamp post in the city, so all of Barcelona can join in the pleasure of looking at my healthy brains.”

I gave the doctor a copy and put twenty more on the table for his colleagues and family members. I got some pills for whenever I make myself dizzy. I didn't have to pay for them; the neurologist said

that the opportunity to look at such beautiful brains had been payment enough.

Or did he say something else? I'm not entirely sure any more. But I do know for sure is that I went whistling onto the street. I whistled and I sang, at the same time, because it was true – I've never seen such beautiful brains in all my life!

Real art

I still can't get over it, the incredible results of my MRI scan. Everything fell within the limits of the normal. It sounds much more beautiful in Spanish: *dentro de los limites de la normalidad*. I fall within the limits of the normal. For the first time in my life.

The accompanying letter is lovely: a sleek, modern poem, with words that don't rhyme but do have a catchy rhythm. But even lovelier are the illustrations, the photos of my normal brains. They're mostly repetitions of the normal. And if you repeat something that's normal, it's suddenly not normal any more – it's extraordinary, extra-ordinary. It reminds me of the photos about the power of repetition that I like so much, the minimal art that I pay maximum prices for. And this was cheap. All I had to do was lie down a minute and get an injection of colored fluid so my brains would show up nicely. It's my work of art, my very own work of art.

So I've decided to shove Roni Horn and Thomas Ruff off the wall. I'm going to hang there myself with all my brain lobes that fall within the limits of the normal. Would the Central Museum be interested? Would it organize an exhibition of normal lobes? Even if not a single museum shows any interest, I'm keeping them. And I'm going to enjoy them. Every time I look at my own lobes with my own lobes, I'm going to enjoy them.

Birthday

Today my brother Victor would be forty-five years old. What would he look like at forty-five? It's hard for me to imagine him as an almost 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, when the day passed like all the others. 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 "without a jacket" because it was a beautiful summer day. My youngest aunt, who would become his godmother, walked up to me. She was wearing a white dress with big red flowers printed on it. 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. I told Victor that story every year on his birthday. It became a running gag between us – I always wanted to tell it to him again, and he acted as if he were hearing it for the first time, just to please me (and to please himself, too).

I can't congratulate him anymore, of course. No more reason to. You congratulate someone because he or she has lived so many years and is marking it on that day. If the person didn't make it, you can put a flower on his grave and mourn the fact that contact is no longer possible. But I'm not big on visiting cemeteries. Tombstones leave me cold.

The ferocity of my feelings surprises me, thirteen years on. But

it's not that they still surprise me; it's that they surprise me again. In the last two 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. I could still remember it all, but it was as if I had heard it through the grapevine. It's gone, I would think with satisfaction. The past has been erased for good.

I used to repeat the test on a regular basis, and to my great relief I found that it was still gone. Sometimes it was extremely awkward, having an empty hard disk, 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.

Recently I started worrying again about little things – a jacket that I shouldn't have bought, a bit of writing that was long overdue, an explanation that could have been more nuanced. I worry about nothing; I'm beginning to be my old self again. I don't let it go full throttle and just hope that it goes away. But since this morning I know it's not going away any more. I cried because I missed Victor *and* because the anesthetic turned out to have been temporary. I cried because I've recovered. At least I did.

The bird I used to be

Two years ago, not-knowing was a liberation. It was annoying that I couldn't read or do simple mathematics, or that I didn't understand anything about films and television, but at the same time in the aftermath of my encephalitis my life stayed light and tidy. Only the present moment was real. I made no demands on myself. All I had to do was learn to walk, step by step, without falling over. Now I walk without thinking about it, as straight up as I used to and a bit more resolutely. I can read again and write and plan and organize. The only reason I don't feel like my old self is that I can't remember very well what my old self was like.

And I still don't want to know. I cherish the illusion that all the stuff I learned is gone for good, like a computer virus erasing parts of a hard disk once and for all. Years of acquired twists and turns are gone; only the core remains.

That not-knowing wasn't always practical, but I enjoyed traveling without baggage. I had a sense that I was moving faster without having that trunk full of old junk to drag around. Life in the now is the ultimate freedom, which is what every newborn baby knows. The idea that it's never going to be any different is part of that freedom.

In recent months I've noticed, to my great astonishment, that I'm really getting better. The future is beginning to thrust itself upon me and often casts its shadow over the past. No matter how sunny I try to imagine that future, each moment that I'm there is a moment not spent in the now – and that's a damned shame.

Longing is the engine that keeps us going, but it's difficult to long for something that you can't imagine very clearly. It's easier to hanker for something we know well, something we've experienced personally. Two years ago I longed for the previous year, when I still

knew everything and could still do everything. Now I'd very much like some of that innocence back – I long for my own virginity, even though the first wedding night is long past.

Wanting to hold onto everything all the time is exactly what used to weigh my life down so much, and once again I'm catching myself not only wanting to lay my hands on what is but also – and especially – wanting to lay them on what's still to come. I want to feel the future; I want to possess it now before it happens.

Wanting to hold onto everything all the time turns my head into the narrowest cell. There's no prison more claustrophobic than the one you build for yourself. Now that I'm standing on my own two feet again I look wistfully at the bird flying over my head, the bird I once was. I've got to make my peace with the lucky dog I've become.

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