



Translated extract from

Helmut Dubiel
Tief im Hirn
Carl Hanser Verlag
München 2006
ISBN 3-446-20793-7

pp. 7-23, 140 - 142

Helmut Dubiel
Deep within the Brain

Translated by Philip Schmitz

© 2006 Litrix

Prologue

From the Wetterau rest stop the Taunus drops off sharply toward the south. When the sky is cloudy or overcast, the reflection of the lights of Frankfurt can already be seen early in the evening. The glare of the oncoming headlights blurs with the far-away lights of the city in the smeary film the windshield wipers leave behind. I'm driving slowly in the right lane, stuck between two trucks from Poland. I take my hands off the wheel. A passage from di Lampedusa's "The Leopard" comes to mind where the Prince contemplates which moments of his life he would like to relive when he faces death. I have recalled these lines so often that they have blazed a trail of dreams into my sleep. Lately, of course, the memory is tinged with alienation. I'm disturbed by the briefness of the time that the Prince would like to relive if he were given the opportunity. And his choice of wishes bothers me. He wants to relive only his unequivocally happy minutes, for example, the moment he awaits his bride on a flower-scented bed of love. As a petty bourgeois perhaps I am less choosy than the Prince. Perhaps I am also the contemporary of an age in which people have learned that everything has its two sides. For me, there is simply more that comes to mind: my arrival in New York as a dishwasher on board the passenger liner "Europa" in the late 1960s. In those days the structural work on the World Trade Center had just been completed, and the twin towers came into view in the early morning fog. The sight of the active Kilauea Volcano in Hawaii by night. The Iguazu Waterfalls, the endless roads of Patagonia, the sight of the stars over Sinai in the 1970s. The irrepressible happiness in the face of my son when I picked him up at kindergarten in Florence in the late 1980s. The joy – it is difficult to describe – of experiencing how a text created at my desk is read and discussed by many people. And, not to be forgotten, love.

Evidently, it's not only the number of my moments of happiness that distinguishes me from the Prince. In his life the good and the bad, beauty and horror were clearly distinct from one another. In my life, however, happy and unhappy developments do not unfold in parallel, with no connection, but are instead superimposed on each other in often bizarre patterns. For example, when I think back to those days in New York, as a dishwasher on the old "Europa," I cannot help thinking about that 11th day of September in 2001 when I watched from a rooftop in Brooklyn as the two towers collapsed. In a similar way the experience of love and commitment in my life is knotted together with a sense of fear and guilt, betrayal and infidelity, with memories of my wrongdoings against others and theirs against me.

I'm sick. Remembering the beginning and the course of the illness brings my trail of dreams to an end. When I arrive at that point, a sleepless night lies ahead of me. Fifteen years ago I "had" the disease the way other people have diabetes or osteoarthritis. Today, as ever fewer people are capable of differentiating between the disease and me personally, the disease has me. It inundates me with interfering signals, the fluctuating effects of the medications with their constraints and the incessant agitation. Initially, this identification with my illness has to do with its incurability, and then with the fact that it impairs the very physical communicative competencies that people employ to establish relationships with others.

Nevertheless, given the choice between living in the body and mind of some other (healthy) person and continuing my life within my own, I wouldn't hesitate for a second to decide in favor of myself.

I was startled by an earsplitting horn that was blowing as loud as a ship's siren. My car had drifted into the middle lane and a truck was bearing down on me at

high speed from behind. There was a harsh crack. Only after the truck disappeared into the night honking furiously, did I notice that my side mirror had been torn off.

I

In an atlas of neurology the various provinces of the brain are represented in much the same way as the regions of the earth on a geographical map. Deep within the brain, about where the cerebrum tapers into the brain stem, we find the so-called “substantia nigra,” the “black substance.” Leading from the “black substance” to a neighboring area called the “striatum” is a narrow band of tissue only a few centimeters long. The striatum is the home of dopamine, one of the brain’s messenger chemicals that has responsibility in the human building plan for controlling and coordinating the body’s musculoskeletal system. This region of the brain, which is no larger than a walnut, controls the infinitely complicated interplay of the muscle groups that is required, for example, for a person with an awareness of her own dignity to stride vigorously and elegantly through a ballroom. Just as the showman in a pedestrian zone, who becomes rigid like a statue, is only able to perform by virtue of the neuro-muscular control required to coordinate the ever-changing sequence of excitatory and inhibitory impulses.

Parkinson’s disease (PD) attacks predominantly older people between the ages of 55 and 65. The probability of developing the disease increases with age. Epidemiologists, those who study the spread and prevalence of diseases, use the following rule of thumb: Parkinson’s occurs in roughly one percent of those over 60, two percent of those over 70, etc. In more precise terms, Parkinson’s occurs in close to 0.16 percent of the total population, striking 16 out of every 10,000 people. Accordingly, Parkinson’s is considered a “disease of the elderly.”

I was 46 years old when I was diagnosed with the illness, which makes me a case of “young onset Parkinson’s,” or YOP. It is often alleged that the age of onset is dropping. In other words, people are supposedly falling ill at an increasingly young age. It is difficult to obtain statistics about this. The growing number of cases diagnosed under the age of 45, and even under 40, could just as easily be the result of improved diagnostic techniques. Moreover, people who fall ill at an early age get a lot of public attention, so that mass-media awareness of Parkinson’s disease has increased.

The causes of Parkinson's are unknown. The many promises of brain researchers notwithstanding, a scientific breakthrough which would explain PD and provide a cure has as yet failed to materialize. There is good evidence to suggest that the discovery of the causes and perhaps even a cure may emerge from the partial results of the molecular puzzle that are currently being compiled with great energy.

Another reason why Parkinson’s is viewed as a disease of the elderly is that its symptoms are embedded in the unspecific motor disturbances that almost everyone develops at an advanced age. A general stiffening of the muscles, a certain rigidity of movement and a slight tremor are by themselves not symptomatic of an illness. However, to state that a mild case of Parkinson’s manifests itself in almost every aging process would be to trivialize the matter. Perhaps one might say that the aging process derails. In Parkinson's, they say, the substantia nigra “dies.”

The signs of the disease do not present themselves with empirical precision. PD can be “masked” in nonspecific back pain or depression for many years. In the end, a diagnosis is based on the traditionally observed motor disturbances as

well as an interpretive evaluation of the symptoms within the individual's life cycle. The final piece of information has only become available through the most recent medical technology. By using a radioactive contrast medium and so-called "positron emission tomography" low activity in specific areas of the brain can be imaged with absolute certainty. But the procedure is expensive and is only administered in ambiguous cases. Generally, the specific quality of the motor disturbances and the patient's response to L-dopa, the first line medication, will allow a sufficiently precise diagnosis.

In Parkinson's disease, named after its discoverer James Parkinson, the tissue that produces dopamine dies at a faster rate than would correspond to the normal aging process. Naturally, it is not the lack of dopamine alone, but rather the imbalance it causes in other messenger chemicals such as acetylcholine, noradrenaline, serotonin, etc.

The illness does not affect gross motor skills alone, but rather the entire musculature. For example, no area of the body has more muscles than the face. Thus, a pathological deficiency of the messenger chemical dopamine impairs not only the movement of the trunk musculature but also the entire range of a person's individual self-expression. Human beings are more than just animated machines; they communicate not only through speech but with their entire body. One of the unmistakable signs of this disease is the frozen appearance of the facial expression or even the occasional involuntary grimace. This often has dire consequences for the social acceptance of Parkinson's sufferers. What the professional views as a symptom that can be compared objectively to the symptoms of other patients, the layperson construes as a bizarre trait of this particular individual. People who can no longer control their facial expression can also no longer reckon with the average person's willingness to distinguish between the disease and its victim. There are moving accounts of Parkinson's

sufferers who gradually went to pieces because people, their colleagues at work, who did not know of their illness derided them as drunkards, imbeciles and malingerers.

The symptoms that identify Parkinson's and play a major role in traditional diagnosis, are divided into tremor, rigor and akinesia. "Tremor" refers to the hands shaking in a resting position, "rigor" to the stiffening of the entire body musculature, and akinesia to the poverty of all body movement. In the early stages the distribution and severity of all these symptoms are still highly individual. There are patients who suffer visibly only from tremor. Another type of patient exhibits primarily the symptoms of hypokinesia and rigidity. As the years wear on, however, the nature of the symptoms becomes more uniform, so that one might have the impression that the patients are all related to one another. Only a small amount of training is required to recognize full-blown Parkinson's in everyday life. Patients stand in a slightly forward-flexed posture as if they were about to fall over. Their eyes look down at the ground. There is a poverty of facial expression. To the healthy observer, their body posture seems to signal a frightened submissiveness.

From the perspective of the victim, it is of necessity a particularly depressing fact that the first symptoms only emerge when more than half of the substantia nigra has already been damaged. When the first tremor appears, when one often stumbles or stutters, when one's left arm hangs down from the shoulder joint with so little swing that an automatic wristwatch will no longer wind by itself, it's already too late. But speaking of "too late" draws a false analogy to illnesses where an early diagnosis still holds out the promise of a cure. For PD there is as yet no such cure. Nevertheless, all of the advice books, especially those written by physicians, recommend early diagnosis because it creates greater flexibility for prescribing individually tailored medications. Naturally, this advantage must

be offset against the disadvantage of early knowledge. It is, after all, best to know of an inescapable fate as late as possible.

The so-called “gold standard” in drug therapy is L-dopa. A substitute material that is converted into natural dopamine inside the brain, L-dopa utilizes the ability of nerve cells to produce dopamine far above their natural capacity, at least for a time. After a certain period, called the “honeymoon” by neurologists with romantic irony, almost all patients develop side effects. These are large involuntary movements, and in the end it becomes altogether impossible to say whether they are a direct result of the disease or of the medication. During those last years there were days when I was easily swallowing up to 30 pills. Of course, I wasn't taking each of the pills according to my symptomatic needs but was following a “medication regimen” determined at the time by the neurologist who was treating me. Being dependent upon medications to that degree is a torture, a kind of medically prescribed drug addiction. The myriad pills must be taken in a certain sequence. Deviate from the path, either deliberately or inadvertently, and punishment swiftly follows. If the organism is undersupplied, it lapses into an “off period” causing a rigidity that affects the entire musculature and can be very painful. In the event of an accidental overdose, the organism succumbs to disruptive, socially conspicuous dyskinesias and agitation.

In the meantime there are a considerable number of new medications that are unusually geared to complementing the shortcomings of L-dopa, the so-called “agonists.” These are pills which are effective against the core symptoms of Parkinson's. As time goes on, every patient suffers from additional symptoms arising only indirectly from the disease. Many suffer from constipation, swallowing disturbances, speech disorders, back pain, depression, insomnia etc., which are also treated with medications. The entire regimen is crowned with

medication for the gastrointestinal problems one might expect as a result of the excessive medication intake.

At present, the pharmaceutical treatment strategy is still dominant, but for about ten years a “new” surgical procedure called “deep brain stimulation” has been practiced. If only for financial reasons this surgical technique will never have the importance of drug therapy. According to the current status of medical research only 15 percent of Parkinson's patients are candidates. Deep brain stimulation involves sending weak electrical signals to the affected regions of the brain by means of a pacemaker implanted in the body. The fact remains, however, that neither the pharmaceutical approach nor the surgical procedure – their great efficacy notwithstanding – alter the underlying degenerative pathology of the tissue in the substantia nigra. They alleviate the consequences of the degeneration, but they do not cure it.

One of my many inklings that I was afflicted with Parkinson's came in the early 1990s. It was the most beautiful day of my life to date. In late May I had driven from Vienna to Lake Neusiedl with Corinna, who at the time still embodied the promise of a great love for me. I still vividly remember our room, the clatter of the breakfast dishes in the small bed-and-breakfast, and the curtain in front of the window billowing in the summer breeze. We made love. At the climax I trembled over my entire body. For several seconds my left hand took on a life of its own and made erratic, chaotic movements. I explained these symptoms, to myself and my lover, as the result of my inordinate passion. And maybe this interpretation was not incorrect. In spite of its bizarre dimensions I failed to take this symptomatic event seriously because it was framed within the beautiful context of love.

From then on symptoms began to appear at increasingly short intervals. In retrospect they fit together to form a clear trail. As a part of everyday experience, though, they were difficult to interpret. There were bothersome sensations that manifested in both mental and physical form. There was an almost constant feeling of stiffness, roughly comparable in degree to the loss of agility and flexibility that healthy people experience after a day of skiing if they are not conditioned. In addition, there was a slight tremor when my hands were in a resting position, which was barely noticeable in my case. Dizziness, which I dismissed as a circulatory problem, was rare. As time progressed, I had a growing, fundamental sense that I was no longer in control of my movements. I felt like a worn out car where the steering responds very imprecisely and only after long seconds.

The panic attacks were the worst of it. The first of them, which I can still remember exactly, befell me at the airport in Pisa. I was in the waiting room after having my hand luggage checked, when I suddenly had the impression that the ceiling was being pressed down toward the floor by a gigantic vise, and that it was threatening to crush me. At the same time, something told me that it must be an illusion because my fellow passengers were evidently noticing nothing of the kind. I, however, was struck from one moment to the next by diarrhea, difficulty breathing, shaky knees, chest pain, and sweaty hands.

Only in retrospect was I inclined to see in this first panic attack a causal connection with a minor incident that had occurred immediately beforehand. The waiting room was sectioned off from the apron of the airport by a plate glass wall. Suddenly, in a group of passengers heading for their airplane on the other side of the plate glass, I recognized an Italian woman whom I knew in passing. She had once been my language teacher, and my memories of her were not pleasant. She had poked fun at my Teutonic stiffness. I now drew attention

to myself by waving my hand in a choppy motion I perceived as typically Italian. She separated herself from the group along with her partner, laughingly pointed me out to him, and then repeated my choppy hand motion with openly sarcastic intentions. Her mimicry of my gesture immediately made it clear to me that from the perspective of an external observer my expressive behavior was already a far cry from the internal image that I, like everyone else, carried of myself. My actual expressions were no more than a caricatured, distorted representation of their underlying intentions.

I was and continue to be a university professor, and at the time I had a large circle of acquaintances, colleagues and friends. In addition, I was the father of a boy who was entering elementary school during the period I am describing. The very day-to-day responsibilities, tasks and activities of daily life such as driving a car, especially chauffeuring children, teaching students, not to mention giving lectures, became a source of harrowing anxiety attacks. And yet it took several years before I was even able to interpret the various physical indications such as stomach ache, shaky knees, a tendency to diarrhea and racing heart as signs of anxiety and panic. All of these conditions together with almost constant fatigue and diffuse pain in my limbs made it clear to me that something was fundamentally wrong. When my very first symptoms appeared, I would still discuss them with several confidential, generally male friends. But they were as clueless as I. It was precisely the parallelism of physical and psychiatric symptoms that was so confusing. The more they coalesced into a neurological picture, the more I kept silent about them.

I was so distraught because in those days, early in the last decade of the 20th century, I still believed that it was possible to achieve happiness not just momentarily but as a condition, so to speak. It wasn't my bitter but as yet abstract premonition of being gravely ill that clearly demonstrated how illusory

this expectation was. Rather, it was experiencing the diverse fears, the daily impairment of my lifestyle and the constant, inexplicable exhaustion after performing tasks that had once been a source of joy, that permanently darkened my horizon. The Matthew principle also applies to those who have been saddened: misfortune is heaped on the unfortunate.

Corinna from Vienna, whom I thought I loved more than anything else at the time, could no longer endure the hiding game she was playing with her partner who had turned mistrustful. The mountain of lies that our love was built upon stifled the magic of our nights. She hadn't said anything, but we both knew, and each of us was aware that the other one knew, that our farewell at Vienna Western Station in June would be the last time we met. I had a foreboding that the short happy spell was only to be an incubation period for an unhappiness that would last until my death. I suddenly recalled insights that had once been at the forefront of my mind. The realization, for example, that one can only achieve happiness or even contentment in life through one's own effort, and that the inclination to borrow expectations of happiness against a romantic attachment will destroy the happiness over the long term.

I learned only later through studying clinical accounts and the experience reports of patients that the outbreak of dramatic, chronic and especially neurological diseases is often accompanied by nonspecific psychophysical states of exhaustion. The fact that serious diseases often use psychophysical breakdowns as a Trojan horse may mislead one into interpreting the underlying disease process in a simple, psychosomatic sense. To me, the hypothesis of an emotional immune system would appear more fitting. In addition to an intact physical immune system, every person who is physically and mentally well enough also possesses an emotional immune system, The latter can be so weakened by

numerous traumatic stressors that it collapses resulting in the manifestation of a pathology which was long present in a latent, germinal form.

I was already standing on the lowest step of the Vienna–Amsterdam night train which was cleared for departure. At that moment, time stood still, and I mean literally. At the minute the train was scheduled to leave, some esoteric defect for which there would also be no comprehensible official explanation later on, paralyzed all of the clocks in Vienna Western Station.

But this wonder only impressed the train's engineer for several minutes. Our love had been strong enough to stop the clocks in the station but not the train, the further course of events and time itself. When I arrived in Frankfurt the next morning, shattered and poorly rested, my legs buckled underneath me on the platform. The emergency doctor had me admitted to a hospital for a neurological examination.

(...)

EPILOGUE

Near the exit for Friedberg the valley carved into the Taunus hills widens into the Rhine-Main plain. In the distance one sees the skyline of Frankfurt, embedded in a panorama of small parks and postmodern industrial buildings. I was still feeling the shock of my collision with the truck. I would have liked to be driving slower, especially since the remains of my side mirror were still attached by two spiral wires and the oncoming wind was rhythmically knocking it against the body of my car. But I was surrounded by vehicles that were all driving very fast, as if they were attracted to the scent of the nearby city. In the

meantime, dusk had turned into the still-light darkness of an early summer evening. When the heavy traffic finally gave me an opening, I switched into the right lane and headed for the Taunusblick rest stop, where I parked my car between the huge, dark trucks. In the twilight of the parking lot lights, and with their roaring refrigeration units, they seemed like a herd of primeval monsters. Using a pair of pliers I separated the wrecked mirror from the body of the car.

Over the last few months I have tried – with some success – to secure the positive stocks of my life rather than lament what I am no longer able to have or to do. Thus, I have begun to reconcile myself with my pacemaker. It gives me energy and mobility. I can accept it now because I more often take the liberty of turning it off. Then I can think, talk and formulate thoughts as I speak just like before, as if nothing had ever happened – although only for two hours.

After much training I am now capable of walking for two hours. I have my medication regimen under control. New medications will appear on the market and relieve the dizziness that often plagues me. Of course, I must resign myself to being viewed as “handicapped.” This, in turn, is bearable because many people show me that they like me and thereby convey a more positive self-image to me than I had before my illness. And I have begun to follow PD research on the Internet, again. Just as deep brain stimulation gripped my attention several years ago, it is now “spheramine,” a magical word that reminds one of precious stones. This involves the implantation of human retinal tissue into the putamen area of the brain, which promises a more effective treatment of PD.

I do not know whether I can still reckon with a significant improvement of my symptoms – someday. But I don’t want to stop dreaming about the things I will

eventually be able to do again: walk through large crowds of people without fear, dance, talk with strangers in noisy train stations, stroll along the path that leads from Harlem down to Battery Park, on a sunny September day in New York.

The preconditions and consequences of all the important decisions in life are too complex for the individuals involved to be fully aware of them. That should not offend our narcissism in any way. On the contrary, one of the prerequisites for happiness is realizing life's open-endedness and having an inkling that beyond the next mountain range, around the next bend in the road, lies an unknown land.