

The meaning of being-ill

Jan Hendrik van den Berg

If we wish to realize what it means to be ill, we should begin by trying to remember what happened when a short, passing, but positively uncomfortable, illness made us stay in bed for a few days. What will come back to us might be something like the following report.

Report by the father of a family

After a restless and disturbed sleep, I wake up in the morning, not feeling too well. I get out of bed, however, intending to start the day in the usual manner. But soon I notice that I cannot. I have a headache; I feel sick. I notice an uncontrollable urge to vomit and I deem myself so incapable of facing the day that I convince myself that I am ill. I return to the bed I just left with every intention of staying there for a while. The thermometer shows that my decision was not unreasonable. My wife's cautious inquiry whether I would like something for breakfast makes the reason much clearer. I am *really* ill. I give up my coffee and toast, as I give up everything the day was to bring, all the plans and the duties. And to prove that I am abandoning these completely I turn to the wall, nestle myself in my in my bed, which guarantees a comparative well-being by its warm invitation to passivity, and close my eyes. But I find that I cannot sleep.

Then, slowly, but irrevocably, a change, characteristic of the sickbed, establishes itself. I hear the day begin. From downstairs the sounds of household activities penetrate into the bedroom. The children are called for breakfast. Loud hasty voices are evidence of the fact that their owners have to go to school in a few minutes. A handkerchief has to be found, and a bookbag. Quick young legs run up and down the stairs. How familiar, and at the same time how utterly strange things are; how near and yet how far away they are. What I am hearing is the beginning of my daily existence, with this difference, though, that now I have no function in it. In a way I still belong completely to what happens downstairs; I take a share in the noises I hear, but at the same time everything passes me by, everything happens at a great distance. "Is Daddy ill?" a voice calls out; even at this early moment, it has ceased to consider that I can hear it. "Yes, Daddy is ill." A moment later the door opens and they come to say goodbye.

They remain just as remote. The distance I measured in the sounds from downstairs appears even greater, if possible now that they are at my bedside, with their fresh clean faces and lively gestures. Everything about them indicates the normal healthy day, the day of work and play, of street and school. The day outside the house, in which 'outside' has acquired a new special meaning for me, a meaning emphasizing my exclusion.

I hear that the day has begun out in the street. It makes itself heard; cars pull away and blow their horns, and boys shout to one another. I have not heard the sounds of the street like this for years, from such an enormous distance. The doorbell rings; it is the milkman, the postman, or an acquaintance; whoever it is I have nothing to do with him. The telephone rings; for a moment I try to be interested enough to listen, but again I soon submit to the inevitable, reassuring, but at the same time slightly discouraging, knowledge that I have to relinquish everything. I have ceased to belong; I have no part in it.

The world has shrunk to the size of my bedroom, or rather my bed. For even if I set foot on the floor it seems as if I am entering a *terra incognita*. Going to the bathroom is an unfriendly, slightly unreal, excursion. With the feeling of coming home I pull the blankets over me. The horizon is narrowed to the edge of my bed and even this bed is not completely my domain. Apart from where I am lying it is cold and uncomfortable; the pillow only welcomes me where my head touches it. Every move is a small conquest.

Change of the future and the past

The horizon in time, too, is narrowed. The plans of yesterday lose their meaning and their importance; they have hardly any real value. They seem more complicated, more exhausting, more foolish and ambitious than I saw them the day before. All that awaits me becomes tasteless, or even distasteful. The past seems saturated with trivialities. It appears to me that I hardly ever tackled my real tasks. Future and past lose their outlines; I withdraw from both and I live in the confined present of this bed which guards me against the things that were and those that will be. Under normal circumstances I live in the future, and in the past as far as the future draws upon it to prescribe my duties. Apart from a few special moments I never really live in the present, I never think of it. But the sickbed does not allow me to escape from the present.

Normally I am not aware of my body; it performs its tasks like an instrument. Now that I am ill, I become acutely aware of a bodily existence, which makes itself felt in a general malaise, in a dull headache and in a vague nausea. The body which used to be a condition becomes the sole content of the moment. The present, while always serving the future, and therefore often being an effect of the past, becomes saturated with itself. As a patient I live with a useless body in a disconnected present.

Everything gets an 'actual' meaning, and this is quite a discovery for us who are pledged to the future. The telephone, rather than conveying the message from the person at the other end of the line, makes me aware of the fact that, as a frozen appeal,

it rings with a new sound through a house which has become remarkably remote and strange. The blankets of my bed, articles so much devoted to utility that they used to disappear behind the goal they served, so that in my normal condition I could not possibly have said what color they are, become jungles of colored threads in which my eye laboriously finds its way. The sheets are immeasurable white plains with deep crevasses, steep slopes and insurmountable summits; a polar landscape to the paralyzed traveller that I am.

The wallpaper which I only noticed vaguely, if I ever saw it at all, has to be painfully analyzed in lines, dots, smaller and larger figures. I feel an urge to examine the symmetrical pattern, and to see in it caricatures of people, animals and things. It is as if I am taking a Rorschach-test, immensely enlarged. Hopeless and nightmarish interpretations urge themselves upon me, particularly when I am running a fever. And I feel I am going mad when I find a spot that cannot be made to fit into the structure which took me such pains to evolve.

After a few days I begin to hate the oil painting on the wall. For by this time I have acquired a certain freedom to change the caricatures of the wallpaper; I can replace the configuration I created by another one when I am bored with it. But the figures in the painting, the people, the animals, the houses and the trees, resist every attempt in this direction. The hunter, about to shoot the flying duck, remains aiming motionlessly, while I have judged his chances a hundred times. And the duck, which would probably manage to reach a hiding place if it is quick enough, defies all dangers as it comfortably floats over the landscape where the sun forgets the laws of cosmography in an eternal sunset. "Oh! please, hurry up" I say, exasperated, and even if I am amused at my own words, I do ask the next visitor to please be kind enough either to turn the picture to the wall or to remove it altogether.

The call of things

As I notice my clothes, hanging over the chair at the foot of my bed, I realize with a new clarity that the horizon of my existence is narrowed. For the jacket there, the shirt and tie, belong to the outside world. I see myself descending the stairs, going to work, and receiving guests. Certainly I am that man, but at the same time I have ceased to be he. The clothes are completely familiar and very near, and yet they belong just as truly to a world which is no longer mine. I feel a vague sympathy for these clothes, which remind me, tactfully, of my healthy existence, which must have had its value. Nevertheless, I am pleased when caring hands change my bedroom into a proper sickroom and my clothes are put away in the wardrobe. For however tactful the reminder is, I do not like to be reminded at all. After all, I cannot and will not put it into effect anyway.

If I am sensitive this way, if I possess the remarkable sense which enables people to understand the language of the lifeless objects, the discovery of my shoes is particularly revealing, even if I find it hard to put into words what these shoes, with their silent and yet expressive faces, have to say. In his famous journal, Julian Green drew our attention to the fact that it is the hat and shoes that are the most personal of our clothes.

None of our clothes is entirely anonymous; they are all part of ourselves in a way, an extra skin, the skin that we choose to show others and which we want to see ourselves. We choose our various articles of clothing with this showing and seeing in mind.

A man has not very much choice in this respect. A suit is a suit; the colors may vary a bit, the material and the cut may depend on the amount of money he can afford or is willing to spend. But that is all the variety at his disposal. A man who respects himself buys a shirt that hardly differs from the one his neighbor or colleague wears. In the matter of ties we are less restricted. The salesman shows us a rainbow of colors and an array of designs. A tie can be a very personal thing. That is why we are not really pleased to find another man wearing the same tie; it seems as if we meet an attribute of ourselves which he has unlawfully appropriated.

And then the hat. Even for men the varieties in color, shape, consistency, hairiness and handiness are almost inexhaustible. It becomes even more personal when the first newness has worn off. The hat acquires dents and creases; the brim gets a twist and a wave. These things are all signatures of the wearer and show his hold on things, his way of life. There are crying hats, proud hats, provocative hats, gloomy hats, tortured hats. And just as they tell us something about their respective owners, they certainly have something to say to their wearers themselves. Will the owner of the gloomy hat not be touched with a certain pity when he sees his hat hanging among happier members of its kind.

Shoes, too, form a very personal part of our clothing. Besides that, they enjoy the extraordinary privilege of having faces. Some shoes shake with laughter; others stare silently upon a vague distance; others again look at us full of reproach. In a store we cannot see these things yet; in their distinctive neutrality they make our choice difficult. But we have only to wear our new acquisitions a few weeks and the personality is there. As a rule their faces are not unlike those of their wardrobe mates. After all, they are of one family. Our shoes constitute our contact with the earth; they tread on country lanes and city streets. Their route is our life's course. Now they are waiting for us, there, by the bed, a silent but futile invitation. The faces with which they look at me completely explain my condition: I no longer belong to the life which none the less is still mine; my street, my road, lies outside the horizon of my existence.

These are a few experiences of a short and harmless illness. Let us see now how a person is affected whose illness is not an incidental intermission, but a long, or even lasting, condition.

Stevenson's ill man

In his captivating novel 'The Bottle Imp' Robert Louis Stevenson tells the story of a man with whom all went well in his life. With the help of a magical power, which lives in a bottle, he has become rich. He buys himself a wonderful house on one of the sunny islands of the Pacific. He has it furnished to his taste, sparing neither money nor trouble. And he marries a beautiful and charming girl who fits exactly into these surroundings. When he wakes up in the morning he sings as he gets out of bed, and

singing, he washes his healthy body. On a certain morning his wife hears the singing suddenly stop. Surprised by the silence she goes to investigate. She discovers her husband in a state of silent consternation. As an explanation he points at a small insignificant pale spot on his body. He has leprosy. At the discovery of this seemingly insignificant change, his whole existence is ruined. It is no longer of any interest to him that he is a rich man, the owner of one of the most wonderful houses in the world. No longer has he an eye for the beauty of his island; this beauty has disappeared; at the most it is an accentuation of his despair. If he thought of the happiness of his marriage just a moment ago, now his wife belongs to the caste of the healthy, inaccessible to him from now on.

Discovery of a serious illness

Every year thousands of people make a similar discovery. The woman who, while taking a bath, feels 'the lump in her breast' puts away the soap and tells herself the terrifying message that death has entered her existence. The man who suffered from constipation for a few months and who hears the doctor say that a very serious operation is necessary sees the scenes of his life change into other ones – and what a difference they make. Less disastrous but no less extensive are the considerations of the student who is told that he has to spend "a few months" in a sanatorium. And those of a housewife who hears that the condition of her heart makes it necessary for her to employ permanent help and that if she does not leave her bed and her easy chair, she may "live for years."

The beginning of every serious illness is a halt. Normal life is at an end. Another life takes its place, a life of a completely unknown nature. Although the patient may anxiously anticipate its sorrows and its sufferings, he never completely realizes what they will be. He considers this life of such low value that he cannot give it a form of its own. It seems to him that it cannot be really lived; it has to be passively endured. The patient feels beaten, bewildered, rebellious or – which is just as unfruitful – resigned. It is an experience of complete surprise, hardly imaginable to a healthy person. One suddenly becomes uncertain about things taken most for granted: the personal function in the existence of others, the necessity or even the indispensability of this function, the faith in a still unpredictable future and the faith in the integrity of the body – even if he theoretically accepts these and similar certainties, they are never *really* certain for him.

And just because access to normal healthy life is barred, this life urges itself upon him with a new promise. The world grows dearer to him than ever. The little daily matters seem more desirable to him than ever before. When Bernanos' village priest knows that he is suffering from an inoperable carcinoma and that his days are numbered, the world flows away from him very rapidly – the experience of lonesome isolation within a narrow horizon – but, at the same time, the world acquires a colorfulness and intimacy that amazes him (Bernanos 1936: 336). He had always believed that the attractions of earthly life had long ceased to affect him. With an incredible

clarity, he remembers his healthy existence. And it is certainly not just a coincidence that the first thing that comes to his mind are the roads on which his feet trod; the road that led home from school when he was a child; the hot *route nationale* in summer and the muddy endless country lanes of his parish and finally the road he sees before him. These are suddenly an urgent incentive to live and work. The certainty of death makes life very much alive. The certainty of a chronic illness stresses the blessings of health. The astonishment felt by the patient at this discovery never really disappears as long as his illness lasts.

Conflict with surroundings

Apart from this conflict with himself there is another, possibly even more distressing, 'conflict with his surroundings': *Le drame avec l'entourage*, says France Pastorelli. In her autobiographical notes on the sickbed of a heart patient she gave us an excellent description of the state of being ill, from which we have borrowed freely (Pastorelli 1933). The conflict with the environment is largely caused by the behavior of the healthy visitors. Whereas the patient never really gets over the astonishment of the beginning of his illness, and the sickbed is never an accepted fact but always an emergency, which, even if it lasts for years and never really holds a promise for recovery, keeps its temporary and incidental character, the healthy visitor quickly removes him from the world of his daily existence and accepts him as a *fait accompli*. Even after the first week the visitors have ceased to look surprised as they enter the sickroom, while it is just this surprise that demonstrates the contents of the patient's life. Even after a month their inquiry "How is everything?" is just as conventional as the gestures by which they put their hats on the bed and their coats over a chair. They barely expect a reply and the patient cannot fail to notice it. If he tries to explain how things are, how those things are that keep him anxiously alert and which hurt and torture him, he cannot fail to see how his words hardly reach his visitors; he can see them think of other things while trying to be interested. He can see them think: "We know,-we have known it for a quite a while, and we know it for the future; our knowledge even includes the slight chances of recovery or the certainty of a fatal end."

The sickbed soon becomes a fact for the visitor whereas it never really becomes a fact for the patient. The way in which the visitor talks about the life which only just a short time ago used to be his own reality, proves to the patient that he has simply ceased to be part of that life. He has become a complete stranger to the visitor, a non-participant, 'just a patient'. Everywhere his place is taken by others. While during the first few days or weeks it seemed that his absence would create problems, now these problems are no longer apparent. No one seems to worry about them. Things are going pretty well without him, he is not needed anymore. So little do people miss him that his absence is not even noticed. They only remember him when the calendar says that it is time to pay the patient another visit.

Of course, all this is never expressed openly; it would even be doing the visitor an injustice to assume that these things occur to him at all. He does not think and speak

without sympathy; he has an honestly sympathetic interest. Yet he cannot possibly stop the patient, who is extraordinarily sensitive in this respect, from looking through his words at the harsh fact which brought the visitor to his sickroom in the first place: the fact that he is a 'patient', a patient in his sickroom, outside of which life – with an "I have ceased to know you" – goes on regularly and sensibly. Whereas the noises from the street, the noises in the house, the new way in which the light filters through the windows in the morning and in which it is superseded by artificial light in the evening, the new appearance of his room with the slightly too large bouquet of flowers and the slightly too expensive basket of fruit, whereas all these things teach him that life outside his small existence has become strangely foreign, his visitors transform this strangeness into a hostile distance, if only by their coming and by their way of speaking.

This is particularly true when they are being tactful. For what else does this mean to the patient than that he has apparently become a person who has to be approached with tact, cautiously, which means, with a certain distance. He belongs to an existence having new norms, where the things that are said and the things that are not mentioned follow other rules than in the world outside. It is largely the visitor who makes this clear to him – he even urges these new norms upon him. The patient finds this particularly true when he wants to speak about his illness.

Justified and unjustified reserve

The visitor cannot be blamed for taking a reserved attitude towards the patient's accounts of his illness. He has a right to refuse to be involved in the particulars of this specific disease, or in the experience of the medical examination and of the treatment. It is a pity that this right is so seldom utilized. For this kind of reserve hardly hurts the patient. But he is certainly hurt when his wish to discuss the state of being ill as a form of life which is hard or impossible to bear, is declined with a trivial remark, or when his urgent questions about life and death are treated with a false optimism, as meaningless to the visitor as it is to him. Many patients suffer because they cannot discuss the problems that really matter to them. It is the healthy person who is to blame for this. It is he who goes through life with a completely unjustifiable levity in these matters.

The contemporary rejection of illness and death

We all fear death and illness. But we do not talk about it, neither to others nor to ourselves. Instead of overcoming this fear by meeting sickness and death openly as the most real possibility of our existence, instead of making contact with it in a serious discussion, we escape from this discussion by acting as if illness and death did not exist.

The present social customs make this escape very easy. Reading Huizinga's 'The Waning of the Middle Ages', we learn that in medieval times sickness and death were

visible for everyone (Huizinga 1924: *passim*). The sick walked in the streets; they sat at the side of the road. The lepers made their presence known by sounding their rattle; their processions were a visible warning of the silent processions of plague and cholera, which harassed Europe with a certain regularity. Death had an appearance which no one could ignore. If a person died, the tolling of the bells made the whole town join in his burial. He was carried to his grave, which was dug in the heart of the town, at the graveyard situated around the church. Death was present all the time and so was sickness.

This cannot possibly be said of our time. The sick are removed from our everyday life. They live in hospitals or institutions. A visitor to these centers of sickness usually notices very little of disease and death. There is singing and laughter; there is hardly any suffering to be seen. For serious patients are moved to private rooms; they are more or less sick in secret. When death arrives the other patients do not often notice anything immediately. But after a while, there are a few whispers. Death steals over the ward like a secret; it should never be seen. Occasionally a dying patient is allowed to go home shortly before the end. While the idea of letting a patient return to his family and his trusted environment for a last farewell is certainly laudable, it also means that death is banned from the hospital. Death is not allowed at this place of healing.

And even for the patient himself, death has to be camouflaged. Morphine is administered to him – of course, only to remove the pain. But the universal secret wish that death should come to a patient while he is unconscious is gratified all the same. The graveyard is no longer situated in the center of the town in most countries. Particularly in the larger cities one has to make a search to find the dead. Their last resting place is outside the city, covered by a dome of green, hidden, and out of the way. Like the camouflaged municipal garbage dump – and sometimes near to it – the graveyard gives the impression of a pleasant garden. The passer-by suspects a magnificent country mansion rather than the realm of death.

The right and the wrong aspects of the rejection of illness and death

Of course, much is gained with all this. It is hygienically correct that the sick should no longer roam through town and country. It is a good thing in many respects that the village no longer has its idiot. It is only humane to give the sick the care they need: it would be heartless to keep narcotic drugs from them if the end is painful, too painful.

But much is threatened to be lost. Psychologically, it is extremely dangerous to abolish sickness and death from our daily life. Psychologically, it is far from hygienic to remove the insane from our everyday existence. Again psychologically, it cannot be considered altogether a good thing that modern civilized man lacks every contact with decay and refuse, thanks to ever more perfect techniques of waste-removal. Wherever these things happen, the perishableness of our existence – actually the first human reality – becomes a hidden and therefore a much more dangerous menace. Sickness and death become catastrophes. To a person who is completely unprepared, they always come as a surprise.

Modern man can be compared to the young Buddha who, being kept away from every human sorrow by his educators, became exceptionally sensitive to everything that did not fit in his artificial paradise. It is certainly not just a coincidence that in our time so much is being thought and written about anxiety and dread. We have ceased to live with the realities of our existence which, just because of this negation, urge themselves upon us in the form of a vague dread. Dread is at the bottom of our seemingly happy and healthy life.

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