

## THE SICK-BED OF THE INCURABLY ILL\*

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Today medicine is scoring triumphs as never before. Our diagnosis is more minutely accurate than ever, and our therapeutic resources are considerable. As a result we are able to improve our understanding of the essential nature of the disease, and to institute really effective therapy. The results are unmistakable. One need only look at the average age as it appears from the death notices in the papers. Assuming that these 70, 80 and even 90-year-old people have enjoyed a truly good old age, we can rightly feel satisfaction at having contributed to their reaching this age of the 'blessed'.

There is, however, another side to this picture. The old-fashioned general practitioner—and many a specialist of a few decades ago—did not always know the true character of the disease. But this did not reduce his therapeutic efforts! It is precisely because his therapy was often purely symptomatic that the practitioner was often forced to be at the patient's bedside to search for such manifestations as might cause him to alter his therapeutic approach. By the very inadequacy of his knowledge he found it necessary to give the patient his full attention from day to day, until the very end. How different it is today! When a patient's condition is to be diagnosed he is 'seized' by the individual doctor or the team jointly, provided with a diagnosis, and then referred to the therapist. During this period the patient enjoys unlimited attention—at least physically—but the attention diminishes as soon as the patient has been through the medical 'mill'.

This is partly because a new group of patients immediately require our attention. *We have no time.* Apart from this, however, we should ask ourselves whether we have a sufficient measure of the right mentality. In many cases diagnosis and treatment do not call for painstaking observation or intensive sympathy during a prolonged sick-bed. But let us ask ourselves, are we capable of offering these in cases in which they are urgently needed? I am thinking, in particular, of the incurably ill.

Those who speak or write about a certain discipline of medicine often do so on the basis of personal experience and with a certain sense of self-respect. To impress on you the absence of such a basis in this address, I will tell you that I work with two ward sisters—heads of the surgical ward in my hospital. However excellently these nurses may have adapted themselves to modern trends, they are none the less of the old-fashioned school. Nothing is more important to them than the correct care of the patients under their management. They do not hesitate to criticize and I am given to understand that I give insufficient attention to my patients as human beings. This, they tell me, holds true particularly for two groups of patients, i.e. (1) those who in my opinion—but not in the opinion of the patients themselves!—are not particularly interesting, and (2) a group of patients who have every confidence in the doctor, but who at the same time

are inclined to take up too much of his time. My nurse-critics concluded that I devoted too little of my time to my visiting rounds, and they found a solution to fill the gap. They themselves took over this part of my duties, referring to me only when they had to. Thus I am occasionally given to understand that my presence at a sick-bed is required in this case or that. This arrangement has proved to be very useful, and it has led me to certain considerations which constitute the basis of this address.

After such an introduction it can be understood that this paper is in fact based on my own failure. There is also another aspect to which I must draw your attention. Although in the course of my talk I may occasionally appear to give an indication of a line of action, it is not by any means my intention to impose my personal conviction on you. I expound my views, but only in the hope that you in turn will form your own opinions on this subject.

### SHOULD THE PATIENT BE TOLD?

In the first place, then, there is the question of the approach to the incurably ill. Should these patients be tactfully informed of the gravity of their condition or should they be left in ignorance? There are differences between various countries in the attitude taken in this respect. In the Scandinavian countries many practitioners cautiously discuss their patients' conditions with them. In the United States it is held that the patient who is incurably ill should be told quite plainly that his life will end within a relatively short time. The motivation of this attitude is that every human being has the right to decide on his way of life. Even if the remaining time is short, the individual should be enabled to decide how to spend it.

How do such people behave after having heard the 'verdict'? In many films and novels personalities are described who accept their fate with courage and manage to give a rich meaning to the last days of their lives. I venture to say that this representation is not in accordance with reality. I am convinced that very few individuals are able to cope with such a situation. Each of us has encountered the patient who—at the very first contact—immediately demands to be told the truth. In the past I occasionally gave in to these demands, and my experiences were unfavourable. Even those who had been quite emphatic that they knew better were greatly tortured by the certainty of the approaching end. I have become convinced that patients should be kept in ignorance for as long as possible about the true nature of their condition.

This view requires some justification. Man must die—even if he is privileged never to be seriously ill or entailed in a fatal accident. The cause of death from age lies in physical wear and tear, but we become aware of wear and tear only as we advance in age. In the same way, as a rule we hardly think of death until age reminds us. Until then we are too young and too strong! It is not until a disaster shocks the nation, or until we have seen the sadness of a departure in our own circle, that we begin to

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think of the fate that must overtake us, who knows how soon and in what circumstances? One person of course, is better equipped to cope with this knowledge than another. Some find it easy to think of their own death on the basis of a philosophical outlook on life. Others—and how very fortunate they are—know no fear, in the certainty of a life beyond this life. Many rely on the support afforded by the Church. But on the other hand there is that large group of individuals for whom any thought of death is a shock. Let us take counsel with ourselves! Many among us are familiar with a feeling of fear leading almost to despair. We are overwhelmed by grief because we shall have to say farewell to all that is dear to us: feelings of helplessness and desolation impose themselves on us. They often produce an anxiety which we can hardly bear. It is for this very reason, that thoughts of our own death are generally brief. We do not want to concern ourselves with such thoughts for long and . . . we need not do so. There are numerous ties to connect us with life in its fullness: our family, our work, and the entire structure of society make their full demands on us a few moments later. We are carried away again by the stream of life as if no end awaited us—especially us. Let us, then, concern ourselves with what we do to our fellow men—the incurably ill—when we impose on them all these feelings, not for a few seconds but perhaps for weeks or months. In doing so, are we not committing them to a struggle which increases the burden of an already grievous sick-bed? Naturally they too must at some time be confronted with the certainty of the approaching end. When this comes, will not that certainty be even more difficult to accept, and will these patients not feel cheated? It may be that something of importance can be observed here: in the fullness of life we soon terminate any thought of death. We put up resistance, and we can do so because we still feel healthy and strong. Experience has shown that the exhausted and deteriorated patient is no longer capable of doing this and . . . no longer wishes to do so. To the extent to which the disease has destroyed the body, to this extent it becomes less difficult to say farewell, and to an equal extent the fear of the approaching end disappears, to be replaced by a sense of resignation and peace in the face of things to come. Should this not be regarded as a great Mercy given us by Providence.

In view of this, then, can we be justified in informing our fellow man of the approaching end while the body, and therefore also the mind, is still incapable of accepting it? Would it not be preferable to let events take their natural course? It must be admitted that many arguments can be presented against such an attitude. One of these I myself will mention: The patient may enter his last sleep without ever having become aware of the approaching end. This would not be right, for every human being is entitled to know when he must take the long stride. Many will wish to settle certain matters with themselves and with their Creator, and to say farewell to those who are dear to them; and there may be other reasons why they wish to face death knowingly. Fortunately, experience has shown that the truth nearly always asserts itself shortly before death occurs. If, however, this should not be the case, then it is doubtless our task to inform the patient at that moment. In my opinion, anyone who bears this clearly in mind, and considers himself capable of coping with this task, can accept the attitude now outlined, viz. that patients should be kept in ignorance for as long as possible and, in fact, until death is imminent.

This means that our attitude at the sick-bed of the incurably ill will be characterized by deceit, and it may well be asked whether the deceit can be kept up. As a rule, the patient himself is a great help. Experience teaches us, almost daily, that these patients are only too eager to hear optimistic expressions and encouraging words—sometimes even against their own better judgment! Yet it must be admitted that things are not always easy for us. Many a patient is extremely distrustful. And often there are depressions—nearly always dependent on physical deterioration—which submit the patient to the gravest doubt. In such cases it is difficult to keep up a convincing approach. Failure threatens. More than ever it is then our duty to persevere in our attitude, which we must not change in spite of what the patient says or his attitude to his surroundings. Only too often the patient attempts to test us at such a moment. Some time ago I experienced a striking example:

A man developed a carcinoma of the caecum at the age of 40. The tumour was extirpated and it was found that metastases had

already formed in the mesentery. The expected relapse occurred and soon a large growth had developed, which was clearly palpable through the abdominal wall. In this case our task for several months was to encourage the patient as much as possible. One day the patient's nurse told me that pretence was no longer necessary; the patient was aware of his condition and had accepted it. I allowed myself to be thrown off my guard, and must admit that I also felt relieved at being able to stop pretending. A few moments later, I stood by his bedside, laid my hand on his shoulder and asked him if he had been able to find peace. His reaction was very peculiar. He looked at me with aversion, shook off my hand, and turned his back to me. I was of course embarrassed and hurried away, feeling that a human being who had just had to cope with such a weighty decision should not be disturbed. I was not satisfied, however, and that evening I returned to him and did something which, I fear, is only too seldom done by any of us: I found a chair and sat down to talk with him. His words, as I recall them, were as follows: 'When a man has been in hospital as long as I have, he can estimate the seriousness of a patient's condition from the behaviour of the doctors and nurses. The severely but curably ill are given the most attention. Less attention is paid to those who cannot be saved and patients whose illness is uneventful receive no attention at all.' And he added: 'You and the nurses have perhaps been rather busy of late. Can you imagine that I sometimes find it a bit difficult to believe in my recovery when I notice your indifference?' And finally: 'I am sorry for having let myself go a bit this morning. I know very well that you would long ago have stopped taking any trouble over me if I were really incurable.' These were words spoken by a man who, shortly before, had emphatically said that he was aware that he was dying! At the same time, however, this incident proved how seriously the doctor had failed in his attitude towards the patients in general! It may be said that patients of this type are demanding. They are! But is this not understandable? Is not our attention the only straw left to which they can cling? Is not their often so childlike, moving faith in our skill the cork which keeps them afloat?

#### *At the Sick-bed of the Incurably Ill*

At the sick-bed of the incurably ill the accent should be placed on this: whatever we say or do, it should always be with such conviction as to enable the patient to be confident in our attempts to cure him. What these attempts are matters less. The main thing is that we say something, that we speak with them, and that we do something. It is beyond doubt that many among us fail in this respect. Whatever our position may be in the medical world, the circumstances in which we work have one thing in common: we have to cope with a lack of time. We are diligently busy throughout the day and we are unable to give to all our patients the time to which they are entitled. This lack of time has placed its stamp on all our activities. Some patients we visit in too much of a hurry, others not at all. What is more natural than that, under these conditions, the slowly deteriorating and the incurably ill—bed-ridden for a long time—are the first to be neglected? Yet this is wrong! Whoever we may miss on our rounds, it should certainly not be these patients. However difficult it may be, we must always give them our attention, listen to the often monotonous tale of their complaints, and prescribe for them with conviction. Yes, prescribe for them! Let us not fail to give them the best medication we can, planned especially against their particular affection. Let us also bear in mind that the medicine should be altered from time to time. And, before anything else, let us see to it that it is we who take the initiative. It has repeatedly happened to me that a patient has suggested that I should try something else, or that I should discontinue a certain medicine. This in itself is proof of shaken confidence, and little is needed to upset it completely. The same holds true for the patient who suggests that we 'might get somebody else in on the case'.

This point should be pursued for a moment. However much one may do his best at the sick-bed of the incurably ill, it is inevitable that one fails in some cases. This may be due to wrong tactics, in that we have been too profuse in venturing encouraging remarks which have not come true! Or the sick-bed may have been too prolonged, as a result of which a certain irritability has arisen between patient and doctor. At such moments it becomes necessary to resort to the assistance of others. The object of such a consultation is to create new hope and, above all, to restore



confidence in the practitioner in charge of the case. Nobody who can see this in the right perspective need ever be ashamed to appeal to a colleague. It is, however, of paramount importance that the suggestion should come from the doctor. In many cases it may come not so much from the patient as from his relatives. Again the same point of view should be taken, even if the suggestion is not made in the direction of the person who—in our opinion—would be the most suitable. I am referring to the tendency to appeal—in very sad and hopeless cases—to those who are special representatives, or not representatives at all, of official medicine such as professors, homeopaths, nature-healers, mesmerists, etc. Among these the professors are the authorities par excellence to restore shaken confidence in the doctor in charge. A professional consultation, therefore, should always be welcomed unless death can be expected at any moment. Of the other consultants, only a few can be expected to behave in such a way as to place themselves beside the therapist rather than in his place. Yet their help should not always be refused although no suggestion to resort to their assistance should be made by us. If the patient or his relatives request it, then under certain conditions we should cooperate. In the first place it should be understood that this cooperation is based exclusively on our willingness to withhold nothing from the patient which may give him peace. Secondly, it must be made quite certain that the therapist's line of action, and especially the care of the patient, can be continued undisturbed. In addition the therapist should claim his right of supervision and to interfere if it becomes clear that the patient is being harmed rather than deriving benefit. By this attitude we are serving our patients' interests better than by withdrawing indignantly or by threatening to do so if the assistance of these representatives of non-official medicine is desired. We must not forget that we ourselves have been unable to cure the patient, and that such a consultation is again exclusively a measure of encouragement and revival of hope.

Much could be said about the application of medicaments. It is important to give the patient something that seems to be directed against his illness. We all know that in the slowly deteriorating incurably ill it is our task to ensure the normal functioning of the organs for as long as possible. Inconveniences such as coughs, vomiting, singultus, urinary or faecal retention or incontinence, dyspnoea, sweating, bed-sores, insomnia, anorexia, etc. should be, and can be, controlled. The appropriate agents are well known, and should be only too welcome to us. For it is precisely these aids that enable us to do something for our patients. But symptom and agent must correspond; the patient may be very surprised if a therapy is continued long after the original complaint has disappeared.

*Pain.* A subject which merits more detailed discussion is pain and its alleviation. We are well familiar with the benefits of morphine and its derivatives, and with drugs such as meperidine hydrochloride, etc. Unfortunately we are equally familiar with their untoward side-effects—and I do not mean the possibility of addiction. This possibility need hardly be taken into account in the case of the incurably ill. It is quite a different matter, however, if long continuance of the pain controlling remedy is liable to cause considerable physical and mental harm, and even shorten the patient's life. This constitutes a difficult problem, which must be solved in accordance with the individual conscience. My own opinion is that generally speaking, it is not our task to prolong life to the utmost limit of time but rather to make life bearable. With this in mind I have at times discarded the thought of surgical intervention when I was firmly convinced that it would merely prolong life without sufficiently alleviating the suffering. This implies that I am in favour of a liberal use of analgesics, started in time and gradually increased in dosage to the requirements of the circumstances.

I am well aware that this line of action in fact means a slow poisoning of the person entrusted to our care, and I am prepared to admit that there is little to separate me from the advocates of so-called euthanasia in the form of an abrupt, forced termination of unbearable suffering. In my country euthanasia is a crime punishable by law. Man has not been given the right to decide on life and death; the 'medical man', however, is bound by duty to do for his fellow man—the incurably ill and moribund—that which can be considered justifiable in accordance with honour and conscience. To me, effective analgesia seems not only permissible, but even indispensable.

### *The Patient's Last Hours*

However, even if we so succeed in alleviating to some degree the bodily and mental suffering of the incurably ill, yet the time will come when the weakened body can no longer resist, and the sick-bed becomes a death-bed.

Can anything be expected from the practitioner at that time? During these last hours, does he still have a task to perform? Many are inclined to maintain that he has not. They consider it befitting that the doctor should then withdraw. Death is so solemn an occasion as to justify the presence only of those who are really intimately related to the dying human being. This means his relatives and, if any other presence is justified, a minister of religion. For a long time I shared this view, which, at least, seemed to me to be the correct one for a hospital surgeon. The hospital doctor—unlike the house doctor—has been in relatively brief contact with the patient. I myself used to remain away from the death-bed but I must confess that it was not only respect for the dying which motivated this withdrawal. Only too well do I know that I sometimes lacked the mental courage. It is difficult to admit failure standing by a death-bed. It is also difficult to be among those who have great sorrow. There is a risk that we may be too much influenced by this lack of moral courage—a risk which was pointed out to me by one of my ward-sisters. And well she might! For do not many of us—as soon as we believe that our task has ended—leave the remaining necessary arrangements only too readily to the nurses with whom we work, whether hospital nurses or visiting nurses? Can they be expected always to have the knowledge and wisdom to carry out their duties in the right way in these difficult hours? Is it right that we, who for so long carried the responsibilities, and regarded this as our proud right, should now withdraw completely? It is obvious that there is at least one thing still to be done by the practitioner—to see that many of the measures he has ordered are discontinued. I have just urged that the incurably ill should be given as much attention as possible, and until the end. In this way we have fought death. Inevitably the moment comes when we must admit defeat; when we must bow our heads and hope that the patient may be allowed to leave in peace, without further interference from us. I am afraid that this rule is often broken, especially so in a hospital. Dietetic measures, injections with antibiotics, analeptics or cardiotonics, blood transfusions and so on, are not appropriate at a death-bed. However, it is the doctor who must decide when these measures should be discontinued. And this alone is sufficient reason why he should be present at the death-bed.

Some may believe that after having completed these arrangements the doctor can permanently withdraw. It is true that all further measures are within the competence of the nurse. However, the dying patient is not always assisted by a nurse, and then relatives may have to take over the task. But will they be able to do so? Will they not be powerless through ignorance of illness and death, and especially through overwhelming grief? Then should the patient depart after having been denied these last acts of love? Cannot the doctor be expected to make himself available during these last hours? But will he be competent to do so? What do we know about the requirements of the dying? We learn little about this at our universities. And subsequently, in practice, how often have we been active and present to the end and when one of our patients died? I do not know how this is in this country. I myself have been through a long period during which I was not more often confronted with the needs of the dying than perhaps once a year.

It was when examining our nurses that I heard the theory of the death-bed expounded. As a rule I was impressed by the candidate's considerable knowledge. But equally often I was overcome by a sense of uneasiness when I considered the demands which these young women would have to meet. This cannot be right. The physical well-being of our patients is our concern . . . until the very end. I have not even mentioned, so far, the spiritual care of the dying. Whether anything can be expected from the doctor in this respect depends on the philosophy of life accepted by the patient and his relatives. On the other hand, it may well be that the practitioner himself is convinced of having a mission, without being asked by anybody. However this may be, we must all regard it as our duty to see to it that spiritual comfort is offered to the dying. Often, therefore, we shall have to give up our place

to the pastor or priest but . . . in some cases the patient prefers to be assisted by his relatives or a trusted friend. Let us bear in mind that we, too, can be such a trusted 'friend'.

I do not know whether many among us will be capable of

dignified behaviour under such conditions. But let us be aware of the fact that we *may* be called upon. If so, let us make ourselves available and let us be grateful. Is it not this very task which may be regarded as the most sublime duty of our profession?