Medicine of the Person. Durham. August 6th 2005.

SAILING ON A LONG COURSE WITH PATIENTS.

I. INTRODUCTION: EMERGENCY MEDICINE AND LONG TERM MEDICINE IN NEPHROLOGY.

About thirty years ago, I had the opportunity to practice emergency medicine. One could call it "medicine in Confetti"; one catches a glimpse of the patient for only a few hours at the most. One must act quickly. For example, one is called to the house of someone unknown for a chest pain at night. One goes there using the flashing light in order to travel rapidly. The diagnosis is one of a heart attack. One puts in place the initial treatment. The patient is taken to hospital as fast as possible. During the journey, one observes him carefully, speaks to him. This short relationship can be intense, especially for him. But one does not usually know what the outcome will be.

This medicine, undertaken "at the gallop", can turn one grey. A serial, moreover, is made of it, thrillingly televised, in which a young doctor, who never has time to shave, saves a life every half hour, thanks also to the help of a young nurse, always a blond, who invariably sponges his forehead while he carries out a cardiac massage ever with a heroic expression.

Thirty years later, the medicine that I practice is almost the opposite of this emergency medicine. Many of my patients are on dialysis whom I have seen three times a week for several years. We "sail together on a long course". The patients and I both know that this course on the high seas will continue for a long time. I am happy with this prolonged partnership; it is an interesting type of medicine. The variety of emergency medicine had a certain attraction, bringing to my attention, according to the outcome of the day, a respiratory distress, a pile up of vehicles, a battered prostitute, a spectacular hysterical crisis. But I was somewhat frustrated not to know what became of these casualties or patients briefly encountered. That kind of medicine did not suit me at all. I have not too much nostalgia for the helicopter. I do not regret the emergency insertion of a tube that can be satisfying but also stressful. And let us say nothing about the blond nurse; moreover one could say the same thing about the insertion of an emergency tube.

By comparison with medicine "at the gallop", or "in small pieces", the medicine in which one charts a long journey is a piece of good fortune and, at the same time, a cul-de-sac.

Among the whole spectrum of skills, that of the doctor is a piece of good fortune. While presenting a technical interest, it is relational. It is a job that always offers the chance to look at another person: one sees his personality, his convictions, his aspirations, his pleasures, his failures, and his fear. One sometimes observes the beauty of his courage, often the misery of his shipwreck. If a not too vain existence requires one to ask the questions "Who am I?" "Who are other people?" "What sense does it make to be together?" Then the doctor has a phenomenal piece of good fortune. The professional activity of medicine is a reminder of these questions: especially if the doctor is sailing on a long course with his patients. Time is necessary in fact to allow the patients and their illnesses to become the effective origin of this questioning. One learns more for certain about a man by taking care of chronic illnesses for several years than by seeing hundreds of emergency cases. As a Vietnamese proverb says, "It is easier to have a child with one woman in nine months than with nine women in one month". It is the case that, among various kinds of medical practice, renal medicine has

especially the chance to follow patients over a long period. One is in contact with a dialysis or a transplant patient over many years.

This good fortune to spend many years with the same patient is also a dead end. During this long journey together, the doctor still manages to take in charge, with a certain effectiveness, a failing organ, in my case the kidney. But more often, the failure impinges on other organs. In addition, the patient often finishes, as he grows old, with interference in his social and family life, between an illness that consumes half his time, a generally altered state and a marital partner also, ill or handicapped. In these conditions, the kidney specialist, who sees his patient three times a week, cannot fail to be confronted by an avalanche of problems, organic, psychic or social, that he is unable to resolve. This leads to a strong temptation to concern himself no longer with all these aspects that, nevertheless, are closely bound up with pure nephrology. The situation becomes more complicated. The dead end is there. The doctor, snowed under, then abandons the sick person while giving the impression that he is still doing what is necessary in his narrow area of competence. But in reality, there is no longer navigation together through the long course. Instead of holding onto a watershed, one limits oneself to be blind to the channels of water as one goes along and, as they remain, one travels without conviction, without coherence and without humanity, right up to the shipwreck.

In this long journey together, that can indeed be an opportunity and equally a dead end. What is it that incites us to develop what we might call “faithfulness”? What is it that prevents us? Let’s begin by seeing what helps us. Then we shall examine the obstacles.

II. **THINGS THAT ENCOURAGE OR HELP A DOCTOR TO BE FAITHFUL.**

In the long run, it is our patients who teach us medicine.

The long-term relationship with the patient is sometimes a true school of medicine. Thus Mrs R calls me back fairly regularly, about every six months, when her bodily symptoms give expression to the imbalance of her being. I am grateful to her, for she teaches me with patience and tenacity the things that my masters in no way taught me. She is a chronic case of dialysis. She is 84 and fairly well. But every three or six months, she complains of a different dysfunction. This is in addition to pains and a slight palsy of a polyneurotic type. An electrological exploration was undertaken. An intense thoracic pain of an absolutely dramatic kind then appeared. The cardiologist took her into intensive hospital care but there was no heart attack. Mrs. R. has had, for several weeks, attacks of nausea, diffuse abdominal pains, diarrhoea and vomiting. A clinical examination proved normal and her weight did not change. When all these symptoms disappeared, spontaneously, she developed insomnia. Then she complained of headaches, vertigo and breathlessness.

Such a succession of pathological symptoms, without an organic explanation, must have a meaning. A spiritual writer, Francois-Bernard Michel, draws attention to the etymology of the word, “symptom”: “one who succumbs with”, or “one who succumbs at the same time”. The symptom reveals itself at the same time as an event that has significance for the sick person. It is thus a signal. Lucien Israel, a psychiatrist, said the same thing in another way. “The point of the symptom is to make possible a relationship with the doctor. It is, in a manner, an effort by the patient to speak the language of the doctor. But beyond this, even the person of the patient comes into play.”

One day, in quite an impulsive manner, in the face of I know what symptom; I finished by saying, without beating about the bush, to Mrs. R., “I am going to prescribe nothing, no

investigations nor treatment: that would serve no purpose. All would take its course . . . but a little later, you would have a pain somewhere else for you can't stop yourself from having a pain. You have a constant need to have a pain somewhere. It is pointless for me to concern myself with it". My colleague was astounded to hear me speak in this manner. But Mrs. R. stopped complaining for some months.

On my part, I sometimes listened to her telling me about her life that had been unbelievably difficult; widowed very young, four children, an unpleasant job selling clothes, three children dead, the fourth in a psychiatric hospital, the need to bring up her orphaned grandchildren and to be involved, for 18 years, with a disabled father-in-law. I told her that she had been energetic and very courageous. One day, when I remarked to her that she would no longer suffer anything at all, she replied: "I need time to get used to that". Never so far had she succeeded in acknowledging that her true problem was not becoming accustomed to her state of chronic dialysis. Through failure to acknowledge this, she was suffering a little everywhere in her body. A psychoanalyst, Marie-Louise Pierson, spoke of this light heartedly with an aphorism: "Nothing is worth the pain of doing without words"!

This break in erratic complaints from Mrs. R. lasted for only a time: As Jean-Claude Jornod remarked, "In medicine, as in love, one can say neither 'never' nor 'always'". Mrs. R. had apparently not accustomed herself absolutely to her chronic state of lifelong dialysis, for the cycle of pains finished by switching itself on again.

I am content to listen to her new complaints. She is content to speak to me about them. A prolonged relationship is alone capable of making this possible. I had proof of this when Mrs. R. complains, as it happens, to another doctor who knows her less well. She then benefits from investigations and treatments that, in my view, are a useless risk.

Thanks to this precious Mrs. R., I now know how to listen to certain complaints, notably pains and nauseas, while not prescribing; an attitude fairly difficult and inconvenient for a somatic physician. I have never yet dared to say to the patient: "You probably have a pain to ensure that you receive attention". I do not feel qualified to speak such a word that would, however, be useless, it seems to me. And even condescending! But Mrs. R. will perhaps finish by teaching me to say such things. Meanwhile, she has already taught me not to be astonished when an inadequate renal patient begins to vomit daily a short time after I tell her that the time has come to begin the dialysis sessions. She has taught me to say to the rather incredulous interns, that these vomits did not justify doing an immediate fibrescopy. She has even enlightened me on the nauseas that I happen to experience sometimes, for example, a professional constraint that, as one says; I ought to have had difficulty in putting up with.

Patients who provide a lesson about life.

Meeting likeable or exceptional people is another reason that spurs us on to confidence in a relationship. In the case of certain chronic patients, it is probable that the handicap or the suffering leads to reflection, to a consideration of what really counts, to drop masks and futile attitudes briefly to see in the situation oneself more clearly. In a marvellous novel by Robertson Davies, "Le Manticore", which my own doctor recommended to me, there is a scene in which a doctor from Zurich says to his patient: "In the course of your illness, you ought to have reflected much. It is that, you know, that helps illnesses . . .".

It is perhaps his illness that has given to Mr. P. his striking wisdom. He has been on dialysis for 2 years. He is now 72. He always speaks of his trials with great calm. He is weak and uses

his hands only with difficulty because of a carpal bilateral canal syndrome. He is, nevertheless, a scholar who reads incessantly. In his house, every bit of furniture is stuffed with books, from the floor to the ceiling. Is it this erudition or indeed his 22 years of dialysis that have made him reflective, lucid and fairly philosophical? Five years ago, a cancer of the breast was discovered with multiple skin metastases and simultaneously a kidney cancer with multiple pulmonary metastases. This is medically very unusual. But the most surprising thing is the dialogue established with this terminal patient. As his custom is, he calls things by their name. We speak indeed during my visit to his bed for dialysis, of “cancer”, of “chemotherapy”, and of “metastases”. This conversation takes place three times a week in a room where there are three other patients on dialysis, who do not miss a scrap of what is said. Is this a strain on confidentiality? Is it exhibitionism? I do not think so. The people in the neighbouring beds are old companions in dialysis of Mr. P. They have often shared his life. Henceforth, they share his approach to death. Mr. P.’s attitude, devoid of a mask, and apparently devoid of fear, is a lesson in living, even if it is a question of dieing. I think that is extremely fruitful. It contrasts with the usual saying nothing on the part of patients who suffer and the habitual avoidance of doctors when they have no solution. The whole room becomes civilized; at least, I hope so. Such a dynamic is possible only during a prolonged relationship.

Sailing with several patients in the same boat.

In nephrology, then, there is a lack of privacy among dialysis patients. This can be an asset in the durable relationship between the doctor and the patient. I make careful use of this less academic asset. For example, in commenting in a loud voice to a dialysis patient, on his last protein blood level, or his last potassium blood concentration, and on giving dietetic advice to reduce the anomalies, I know very well that his neighbours hear, and even listen. This is very useful. For each time that one explains to a patient that he has eaten too much fruit, something that one wishes as advice, inevitably also constitutes a reproach. When I make this reproach to one dialysis patient, and the three neighbours hear it, that means that four people have received useful information on their eating habit, but only one has been reprimanded for swerving into a dangerous regime: a huge economy of aggression. But for the health technocrats, overrunning France, who dictate to carers what they must do, my behaviour is reprehensible. A patient must never hear what is said to his neighbour!

The lasting relationship also allows the patient to know the personality of his doctor. This is not without point. And there again, one can use as a tool the lack of privacy among the beds. Thus Mrs. P., aged 66, is very anxious. She coughs and concerns herself with the cough. As this cough, labelled “spastic bronchitis”, has existed for years, I, in no way, become concerned about it, but I finish be prescribing a radio. The cough is normal. I let Mrs. P. know this, assuring her that there is nothing serious. Seeing that I have failed to reassure her, I put my foot in it, for the sake of proceeding with the problem.

-And no, you have no cancer, Mrs. P. Not yet; not this time.

-Any way, doctor, if I had one, you would not tell me.

-Most certainly yes. I never tell riddles. And if one asks me a question, I always respond truthfully. But certainly, you must ask the question, if you want to know the reply.

Whether Mrs. P. was reassured, I am not absolutely certain. But I am certain that her neighbours in the room will know how to pass the day with me when they have a desire, or no desire, to know what is happening to them.

The hard condition of the patient.

Another situation encourages me to have a long relationship, not secret, but, if possible, sustained. It is a question of the abundant use that is made of anti-depressants. It is our time that so wishes. But “He who marries his time will soon be widowed”, the poet, Joseph Brodsky, maliciously remarked. I reserve the right to be sceptical about this practice.

Dialysis is a hard and prolonged test. About a tenth of my patients are on an antidepressant, usually over several years, prescribed, not by me, but by their general practitioner, rarely by a psychiatrist.

When a patient takes an antidepressant, it is as if he were wearing a sort of label indicating, “I am suffering, I am unhappy”. I then ask some discreet questions about this treatment and its effectiveness. In the majority of cases, to my great astonishment, I note that the patient knows neither that his tablet is called an antidepressant nor what it does. Has he perhaps forgotten? Perhaps he prefers to forget. In any case, it seems to me that this ignorance, by preventing the association of psychotherapy with the molecule prescribed, indicates the presence of a dehumanised therapy that does not take the person into consideration, and that may even deceive him.

One acts as if psychical suffering were a symptom of the same kind as the suffering of a fracture. If that were the case, the pill ought to be able to suppress the depressive symptom without the patient knowing. That seems to me highly unlikely. And if that were true, it would be, in my sight, a very singular situation, for a doctor to accompany his patient.

The simple sadness, resulting from a test, seems to constitute today an indication to prescribe an inhibitor of the serotonine type such as the famous Prozac. In fact, all dialysis patients undergo a serious test, as they are dependent on a machine for life. All live with frustrating renunciations in the present and are fearful for the future. The majority experience regular sadness. Few seem to me to rise again through antidepressants, even if some are unhappy, sometimes terribly unhappy. Here is reason, if possible, to sail with them in a long relationship at the same time as prescribing dialysis. It is true, however, that the therapeutic efficacy of a medical relationship on sadness is not totally obvious but neither is that of antidepressants any more so.

III. DIFFICULTIES IN THE NAVIGATION OF A Long COURSE, OR OBSTACLES TO FIDELITY.

The Patients with whom we are involved for years like to offer us presents. I hesitate to include these patients among the things that incite trust or among the obstacles to it. I accept them with the feeling that they re-enforce the relationship, but I must acknowledge that I often regret that these trinkets, offered to me, are practically unbreakable.

The need for efficiency, and even output.

Chronic illness does not only transform the body. It modifies the whole existence. Thus, when one puts on dialysis an inadequately functioning renal patient, one introduces constraints to his food, his work, his holidays, his resources, his sexuality, his fecundity, the use of his neighbours’ time. Consequently, the patient has to speak with the kidney specialist of his whole daily life, and not only of his symptoms. It is already time consuming. But members of the family would also have a great need to ask the doctor questions, or still what takes even

more time, for the latter, would need to tell him what they note about their relative on dialysis, and what they themselves are experiencing.

The doctor can be led to speak for an hour with the patient, and the next day, an hour with his partner, and again, two days, later on the telephone, to his children or to his social helper. This necessary investment of time is unknown and inconceivable in the eyes of those who today wish to apply to medicine notions of efficiency and output, assuming that to take care of people is a scientific practice based on technical acts.

Mr. N., aged 72, has been on dialysis for 5 years, has been extremely tired for a year, and is despondent at being no longer able to take the long walks in the forest to which he was accustomed. A cardiac incapacity has occurred. Up to now, when asked, he used to sing for half an hour, for his neighbours in the room and for the nurses, on Saturday morning in the middle of his session on dialysis. He no longer does so. He no longer has the taste. He says that the hours of dialysis are an insupportable constraint, and lets himself sink. “That which no longer mobilises, immobilises”, John Pierre Scherding noted. What does one do against this debility? I have modified certain parameters of dialysis and prescribed intravenous injections of iron. The general practitioner has tried homeopathy and antidepressants. Without success. Can the people responsible for administering health understand that the treatment of this debility perhaps requires that I take time to listen as the patient speaks to me of his adolescence, a time when, he tells, he deployed great physical strength? In fact, when I ask him precise details about his tiredness, it is about his long apprenticeship as a fireman that he begins to relate to me at length. If he replies thus in response to the question, it is perhaps because just there lies the problem, and its solution. Paul Tournier, moreover, used to listen to patients speaking by the fireside.

The contemporary need for profitability is the exact opposite of this listening “in the light of the question” in medicine. Thus the administration, and those who pay for the organization, considers that each year we can take more patients into our charge, or achieve more acts, thanks to more efficient tools, like the present generators of dialysis. I think that this is not the case. As Didier Tronchet said, “The technological advances that favour speed of execution reduce indeed the time for mature reflection”. In the domain of transport, they advocate travelling by bike. In the sphere of nephrology, it is counter productive to take thirty consultations a day, as certain of my colleagues say that they do. So much the more so, this obligation to go faster cannot apply to the technical part of the act, for a clinical examination or the imposition of a catheter takes as many minutes today as recently. It is inevitably accomplished at the expense of time for a word. It is, moreover, the word that is jettisoned by the increase in the load of medical tasks. We act, or are made to act, as if care or cure does not depend on listening, on information provided and on empathy. Thorough studies have indeed shown, for everything is shown in medicine! – That the more minutes the nephrologogist spends per week at the bed of his dialysis patients, the less they experience complications.

By working more and more quickly, one works more and more badly. In these conditions, it is with consternation that I see a new patient, the arrival of a new candidate for dialysis. What a welcome for this poor patient. For he must unfortunately perceive what I feel. I would prefer that he were not there. I am tempted to reject him, as on Medusa’s raft, one was tempted to throw into the water the shipwrecked person wanting to hoist himself on board. One more shipwrecked person, one more patient, and that is everybody who sinks when one has no time for everybody.

The consequence of this contemporary obligation to increase the medical output is that navigation on a long course with a chronic patient means a decreasing degree of the opportunity to accompany the person. It is more and more the technical maintenance of an organ. “One does not exist”, one of my dialysis patients recently complained to a nurse, because I had not had the time to pay a visit for several days.

The “old peoples’ residence”, or the ransom of a Promethean medicine.

Mrs. R. is 77. She has been on dialysis for three and a half years. She is a widow, isolated depressed. She has received antidepressant treatment for some years. No one knows exactly for what reason. Psychotherapy has been tried but Mrs. R. quickly asked not to see the psychologist any longer. Three years ago, she completely ceased washing; she began to mutilate her face. She has taken to the habit of demanding oxygen without any reason. When she was at home, it appears, she remained in bed the whole day and ate enormously. The medicaments, which I had prescribed for her, were found in her rubbish bin. This behaviour led to a number of incidents or accidents during analysis. To prevent these accidents was not part of the domain of medicine. They happened because Mrs. R. detested the life that she was living. In a similar case, as Bernard Ruedi said at Drubeck, “promoting health boils down to the priority of promoting love”; or, as Freud said, “one must love in order not to fall ill”. To bring Mrs. R. to love her life and her surroundings was not our responsibility. She was, moreover, unwilling to speak. Every compassionate approach fell on deaf ears. She seemed to be opposed to care without saying so. She made it clear in an infantile fashion. She quietly undid her bandages, for example. She maintained an equal silence about defecating in her bed. I explained to her that I could not dialyse her without her co-operation, and that I would stop the dialysis if she continued her opposing behaviour. In my opinion, she did not want to live any longer, but was unable either to speak about it or to commit suicide.

We finished by making her leave her domicile, against her will, to place her in a hospitalised service for old people. Hence forth, she is correct, calm and no longer disturbs the sessions of dialysis. But she is also inert, silent, and apparently indifferent to everything. I practically never go to see her in the geriatric service. When I go there, I experience despondency and revolt. For me, it is an old people’s residence, not a place of care, still less, a place of life. There I meet old people who seem to me, for the most part sad, without independence and totally unoccupied. Sometimes I see someone strike the nurse in a gesture of refusing care. I then feel, in the light of the evidence, that to withdraw care would be more humane than to pursue it. And, moreover, what can I do, myself? By dialysing Mrs. R., I give her sophisticated care, extremely troublesome and expensive, taken that she does not ask for it and that she seems to live an almost vegetative life deprived of desire and full of sadness. Two and a half years ago, she had a hyper potassium blood level cardiac arrest necessitating a whole night of reanimation and dialysis, which I remember as particularly wearing. I consider today this night of effort an abandonment of sense. It ended in the fact that I now dialyse a human being without having any relationship with her.

This prolongation of life can still provide a good number of years, for medicine has become very effective in retarding the death of people. If I had been in charge of Mrs. R. only a few decades ago, she would already be dead. And even dead several times from infections bound to her confinement to bed, loss of body protein, severe anaemia, kidney failure, perhaps depression. All that is controllable today, with a lot of money, effort and medical technology. Like Prometheus, medicine has acquired powerful means and put them at the disposal of fragile man. As in the Promethean myth, this success has a reverse side. Mrs. R. can no longer die, but she lives in solitude, depression and degeneration. “The greatest evil is to exist

without living", said Victor Hugo. In the case of certain illnesses, with which I sail on a long course my good Promethean tools appear to me sometimes to be the tools of tragedy.

Betrayal.

To betray the one for whom one cares, that is most terrible failure. It does exist. In travelling together on a long course, the patient who knows nothing of the danger of navigation is compelled to have confidence in the doctor to define the hurdle that will better allow the reefs to be avoided.

Does it happen that a doctor betrays this confidence? In my sphere, yes. One must call a cat a cat. For more than fifteen years, when I have had the need to arrange operations for patients, I have put them in the right direction, in order that they might have confidence in me, towards surgeons whom I know to be adequately competent.

In the case of dialysis patients, a small operation is necessary. It consists, more or less, of placing in communication an artery and a vein. A "fistula" is thus obtained, a large vein into which much blood flows. That makes it possible to purify the blood. To possess a fistula that functions well, makes possible a comfortable dialysis. A mediocre fistula involves constraints, failures, suffering, hospitalisation and repeated surgical interventions. The creation of a fistula for dialysis is thus a major undertaking. Sometimes the operation is simple to achieve, and an untrained surgeon succeeds perfectly. Otherwise, only a specialist surgeon will succeed, for example when the veins are in a bad condition, in the case when many samples of blood have been taken in the preceding years.

Ideally, the majority of failing kidneys need operation by a specialist surgeon. There is not one in my region. I have to send my patients 300 kilometres, in their interest. I like to do this and as often as possible, I do so but not as often as is necessary. The obstacles are numerous. It is exhausting to confront the administration that refuses to pay for the transport. It is dangerous, very dangerous, to let it be known that one has no confidence in the ability of a surgical colleague. This disturbs his peace and puts his career in danger. One loses the possibility to care correctly afterwards for numerous other patients.

I cannot, therefore always point my patients to a surgeon who would give them the best chance. This means many failures, many reinterventions, and many complications, sometimes grave ones. Several people, who have undergone operations, have lost a hand, and one is dead. This, for my part, is no small betrayal. I make the cause of this known. I am not alone in being aware of this. My nurses are fully aware of it and we talk about it. I am not the only person responsible for the situation. The Social Security directors and doctors, who try to prevent patients from being cared for correctly, are well informed by me of the consequences of their obstruction. Let us add that this situation is widespread in France, and elsewhere in the world.

For my part, it is clearly a failure of trust. I have spoken about it on several occasions with Claude Jacob, because Claude has studied, near at hand, a consequential failure of the most severe kind, but fairly similar in nature to the cases that we all remember. In 1984 and 1985, doctors gave their patients blood transfusions with material that they knew was contaminated by the virus SIDA. It was probably difficult for them to do otherwise. In no case would they have used such a product in a transfusion for a member of their own family. If one uses this same standard of judgement to gauge my practice concerning fistulas for dialysis, the betrayal is the same.

The absence of true agreement. (Who can command on board?).

During a voyage with a patient on a long course, who is the captain? The doctor, for it is he who knows how to manoeuvre the boat. But who sets the course? The patient, for it is up to him to choose his destination freely. The doctor does not have the monopoly of decision.

A good number of chronic deficiency patients, after years of slow aggravation, do not accept to begin dialysis the very day on which this treatment becomes indispensable to their survival. Their refusal is not an enlightened refusal, for they do not truly know what awaits them, neither about comfort nor about suffering. Certainly, one informs them as best possible, but contrary to what the legislators think and the militants of the sick people's Associations, this information is largely an illusion.

In medical practice today much emphasis is placed on the freedom of choice of the patient. This is called "enlightened consent". The doctor is required to explain to the patient the different possible therapeutic options with their advantages and inconveniences. But is not this a delusion? To believe that one can explain to a future dialysis patient what his life will be like, or to a transplant patient, amounts to believing that one could explain to Romeo and Juliet what their life as a couple will be like after marriage. However it might be, with their meagre knowledge, many terminal kidney failure patients manifest a refusal, more or less strong, on the day when it becomes vital. What then happens? Generally, today, in France, the family and the doctor compel or convince the patient to a change of mind. This is an insidious and a terrible violence. However, we are persuaded that we are doing well. To become aware of our medicine, in such a case, is not civilised but barbarous. It is sufficient to go and see the calm view adopted by the Inuit people of Canada – savages – on illness.

Beside this situation of non-consent, there exists a slightly different case: mutiny or the attempt at sabotage. One is embarked with a patient for years. But he continually obstinately opposes certain medical instructions. He makes holes in the hull of the boat below the floatation line, of course. And the doctor? Well, he takes the rap.

Among my dialysis patients, half a dozen, at least, are mutinous. They are not opposed to this treatment that keeps them alive, but they do not accept half the treatment, neglecting the consequences. The North Americans have coined the term "odious patient" to denote these dialysis patients who do not respect the regimes that one prescribes for them and, because of this, arrive in the hospital in a serious state at any time, obliging the kidney specialist to spend his night on emergency dialysis, and starting again without any embarrassment the following weekend.

There have always been indocile chronic patients; one can easily understand them. But this phenomenon seems to occur for the doctor more today than recently for we have a new attitude whereby the patient sometimes considers himself a banal consumer with the right to impose his will. This is perhaps, an aspect of the collective contemporary illusion, according to which, the normal man, as publicly depicted, knows only, in his life, satisfactions and successes.

The sweetening of the word.

It seems to me, that in order that communication on the long course be possible, it is necessary that the word be sincere.

But in the domain of medicine, a sincere word from the doctor is inevitably hard for the patient to hear. It is generally bad news, unjust or a threat. This is why the doctor is inclined to adopt a euphemism. He minimises the harshness of the diagnosis. In the name of hope, that he must always uphold, it is said, he presents the prognosis in an excessively optimistic fashion. Does this amount to compassion? Or is it deceit? Two examples.

Numerous old, or very old, patients have cervical pains, lumbago, insomnia, and muscle fatigue in activities that previously they carried out easily. This is often not bound to a curable situation, but to old age, that has no going back, a totally banal collection, even if it is inequitable, striking some people and not others. Good sense would wish that the doctor aid the patient to accept his symptom, explaining to him that, unfortunately, there is no treatment to efface the wearing out of cartilages or the fatigue tied up with old age. The patient would often accept such a report, for underneath, he already knows that it is the case.

But he lives in a deceptive society that pretends that one can be young at any age, and that the doctor must be able to remedy any disorder. In these conditions, a realistic explanation on the part of the doctor is bound to be seen as fatalism, and the fatalism as off hand. There is in it an attitude that belongs to the East. One who understood oriental culture, Jean-Pierre Peroncel-Hugoz, notices that what we call pejorative “fatalism” or “resignation” is considered, in the East, “as this passive form of courage that brings about three things, patience, tolerance, and the revitalisation of misfortunes, an Islamic virtue, as it is”.

Second example: The sweetening of the medical word is particularly customary in the case of terminal illness. We think that we manage the patient by hiding from him the fact that his time is numbered. Would it not, rather, be eminently humane to give him indications, permitting him to prepare lucidly, with knowledge of the cause, for this great stage of life that is death? Death is the place where hope and despair meet. If, on the threshold of death, the information that the patient receives about its proximity is deceptive, how can he make provision for this permanent rupture in the bond with his neighbours? How can tenderness take the place of solitude? What is the fundamental reason that the doctor conceals, and hides from himself, the reality of death? Ernest Wiecher affirms in his novel, “The Jerome Children”: “Only he can be a doctor who is a friend of life, and not he who is an enemy of death”.

The solitude of the captain.

The doctor perhaps resembles a captain who places his skill at the service of the patient who has embarked. But because of the difficulties that have just been enumerated, he is a captain peculiarly exposed to doubts. Does he act judiciously? Does the voyage make sense? Doubt is the second name for lucidity. It is indeed necessary to decide every day, which sail to hoist and which watershed to hold for, as the psychiatrist, Lucien Israel, says, “the doctor must doubt but he must not hesitate”. If he does so, he acts in doubt and makes a mistake.

Many people, on land, claim to know better than he what he ought to do. They give him instructions on the radio. There are the ship owners. These are the financiers and public officials they have only managed to supply too small a craft and an inadequate crew, but they want the boat to sail, notwithstanding, without mishap. Then there are the meteorological specialists who plan routes from the shore. These are the researchers and professors of medicine. All these experts speak only foolishly; their technocratic or scientific vision of sailing misjudges the essential. The doctor captain is indeed alone.

IV. FINALLY THE RECKONING: A TRULY SINGULAR VOYAGE.

Sailing on a long course with a patient is a singular voyage. There are certainly excellent navigational instruments. We take care of people with remarkable machines and effective medicines. But there is something that does not reassure us much; **we also provide care with our personality**. As Balint says: “Throughout his professional existence, what a doctor prescribes most is himself”. When one knows oneself a little, how can one not feel seriously deficient? Besides, without feeling oneself necessarily responsible, there is thus without doubt, even today, truth in the exclamation of La Bruyere: “I prefer to deal with a happy doctor than with a learned doctor”. There are probably days when we make ill the patients for whom we care, without being able to do anything at all about it.

Another singularity. We willingly consider that the doctor cures the sick person. It would be more just to say that we take care of him, but it is the patient who heals himself, understood like this when one has not “repaired” him. For in a long-lasting illness, with all its successive complications, to cure is not generally to make the anomalies disappear. It is rather the gift of new modes of life, satisfying, sometimes superior to the former ones, the anomalies remaining. What is useful to the cure is the sickness, and not its disappearance, for the sickness – indeed certain sicknesses at least – is at the same time an alarm signal from the organism to warn the person that his life is not right and an inducement, more or less commanding, to live differently. Such is the analysis made by George Canquilhem. He states it in a short remark: “The organism enables a sick person to cure himself”. It seems to me that the etymology of the word, “depression”, provides a good illustration. De-pressure is perhaps a drop of pressure that comes at the appropriate point, when the organism was submitted to such raised pressures that it ran the risk of explosion.

In the face of such an enlightenment, which looks upon the illness as a means of defence of the living person, what does the role of the doctor become? In the face of ailments, frequently associated with renal failure, such as obesity, diabetes or hypertension, I have come to think, that during these years, I take care of the symptoms, I increase the life span, but I hinder the cure.

Third Singularity. In general, the end of the voyage of a patient on dialysis is more like a shipwreck than arrival in a port. How can one turn this round? That depends on the cases. In certain cases, it is the patient who wishes to go over board. On other occasions, it is the doctor who judges that a person is sinking and that it is time to stop the machines.

The first case, here it is the dialysis patient who no longer supports his situation. He has no longer the taste to continue. “I would be better in the hole!” Mr. C., aged 70, repeats to me. He is a former postman, unmarried, but surrounded by numerous friends. He has been on dialysis for 11 years. He is a chronic polyarthritic. He no longer has the strength to walk more than a few steps. He fears being sent to a care home against his will. This would forbid the pleasures that remain to him, to chat with his friends, go to the restaurant, get drunk alone in the evening at his house. He makes me part of his desire to die, in a direct, serious and repeated fashion. I repeat to him, that, in spite of his desire to go “into the hole”, he has come today, as on every Saturday, to his dialysis session. Everything happens as though he would like to die, but would prefer, at the same time, to be treated. “We, on our part, wish to care for you, but you will not be connected, if you do not wish that to be done.” A long silence. I am not very proud of having created in the mind of Mr.C. such a tension. Have I been too hard? I do not think so. On the contrary, the situation is hard because a place has been left for freedom of choice, a dialogue without false pretence, even in face of the human situation. The nurse, who was

getting ready to make the connection, remains motionless; needle in hand, herself drawn tight. She has had a great and longstanding affection for Mr.C. Throughout the situation there has been respect and sympathy. After a minute, Mr.C. extends his arms to the nurse and says to us: “Connect me”. The desire to die that he showed a few minutes ago is not, however, nullified or effaced. It continues in conversation.

An important minority of dialysis patients affirm that death would be a comfort for them. Indeed, all know that it would be enough to cease dialysis in order to die rapidly and without major discomfort. Nevertheless, none makes a firm decision not to come any longer to the sessions.

Another case. A moment can arrive, at the end of life, doubtless much too late, where it is I, for my part, who think that it must be reasonable to stop these dialysis sessions. I propose this to the patient, trying to be delicate, that is being guilty of a small untruth by omission. In these cases, I never receive explicit agreement. I am content with silence that implies implicit approval. Apparently, in my limited experience, at the end of life when the navigation, on the long course, is complete between doctor and patient, the situation becomes special. This is no longer the time for rational reflection, assumed choice or unambiguous dialogue.

With rare exception, one who is going to die is silent and the doctor, who was accompanying him, just as far as this, accompanies him hardly any longer.

That, then, is our long sail with our chronic patients. Forgive me if I have recounted more than analysed. We are seen to be modest pilots rather than expert captains. It is seen as a question of a difficult, but stimulating, and singular voyage. In such conditions, there is no lack of failures. Our fidelity to the patients, whom we accompany, passes through heights and depths. But do you know of voyages where everything goes well?

Etienne ROBIN.