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“Unhook me doctor, I want to go home”
(When dialysis makes life hard)

Illness can make life hard, sometimes very hard, for our patients. We know it only too well. And our patients know it too: some face up to it, others don't, but in principle all of them correctly surmise that it is illness which is doing them harm. If they had to identify their adversary, they would say '*my diabetes*', '*my blood pressure*', '*my cancer*'.

What a patient with renal failure on dialysis feels is different: the doctor will have explained to him that a disease is insidiously destroying his kidneys; for example, polycystic kidney disease or long-standing diabetes. But in general, dialysis requires a completely different viewpoint of the thing which is causing his body to malfunction. Deep down, the trial that he is subjected to, is not the disease responsible for his renal failure: it is the fact that he is obliged to go three times a week to a renal unit to be dialysed. The injustice which he suffers, has become the treatment which immobilises him on a bed for 4 straight hours: four hours during which he dreads feeling pain and discomfort, four hours after which he is more tired than at the beginning of the dialysis session.

When a patient on dialysis complains, it is never because of their disease. Every time, it is about the burden of their treatment. He must be hooked up every other day to a machine. That imposition is always demanding, generally uncomfortable, sometimes extremely hard, discouraging and harrowing.

Besides, when you ask a patient with renal failure what is wrong with them, they often don't know. Many have forgotten that their renal failure was due to, for example, infections, bladder cancer, excess weight, a toxic antibiotic, or smoking. For the patient, all that is in the past. Those are forgotten enemies. The current enemy is something else. That current enemy has become the dialysis session itself.

To be sure, dialysis is sometimes welcomed and well tolerated: it allows the patient to stay alive longer, to continue living at home, to have a life where relationships are possible, to go on holiday and even to continue to work.... when all goes well. But, given the title of this talk, I'm not here to talk to you about patients on dialysis who are happy that they are surviving on dialysis. I will describe for you situations where medicine makes life hard. In the world of dialysis, that's sadly often the case.

Dialysis has its merciless aspects. It requires you either to get up at 5 in the morning to go to the hospital, or to get home late at night, three days a week. If you don't dialyse you die. But even if you know that it is saving your life, dialysis is perceived as a terrible saviour: it is unforgiving. It is often punishing :

- If someone on dialysis has eaten a bit too much, drunk a bit too much fluid, not stuck to their salt-free diet, they will pay for it. For example, they will be obliged to dialyse for longer than usual: 5 hours of filtration will be necessary, instead of the usual 4 hours. For this, the patients will have a more trying session, with unbearable cramps, fainting, convulsions...
- Or he will be told off by the doctor and the nurse, and will have the impression of being a naughty boy being told off, rather than a patient undergoing an ordeal who is being given solace.
- Or again because of an excess of drink, of food and of salt, the filtration will be too brutal and the patient will be exhausted at the end of their dialysis session: too weak to do anything other than rest in their armchair.
- Under these conditions, if he reflects and tries to find the 'culprit' for his misfortune, it won't occur to him to blame the more or less forgotten illness which destroyed his kidneys long ago: instead, he will curse the dialysis session which is too long, and the nurse who allied herself with the doctor to implement it.

Often, in the mind of the patient on haemodialysis, the enemy is therefore not the renal disease (which nonetheless is certainly present, and about to kill him), but the treatment (even though it is saving his life). That is why it is not uncommon for a patient, even when he is looked after with care and empathy...

... not to tolerate the relentless repetition of his dialysis sessions. He asks or demands that his tubing, which connects him to his dialysis machine be disconnected.: *'Unhook me, Doctor, I want to go home!'*

The dialysis patient knows that his request is irrational: to shorten a session, probably means his next session will be more trying. He will certainly develop the complications of under-dialysis sooner: malnutrition, amputation, cardiac failure... Skipping two or three sessions, or even just one, runs the risk of dying suddenly. The patient is not ignorant of all these risks, since he will have had the risks explained and re-explained every time he dares to pronounce that request with so many meanings: *'Unhook me, doctor, I want to go home!'*

What does this apparent rejection of vital treatment mean?

- Sometimes it is the expression of a passing weariness.
- Other times, it signifies a real desire to end a life which is judged to be unbearable.
- Sometimes, again, it is a cry for help, aimed at the carer, who one would like to be more attentive and more available.

It can take many different forms:

- Complaints, tears, reproaches, bad temper, legal claims.
- It can also be a violent stream of questions, peppered with insults and threats.
- On some days, the patient does something: he causes the dialysis machine to stop by deliberately setting off the alarms: he pulls out the needles through which his blood is circulating, which splatters the blood all over the adjacent walls, the nurse, the patient in the next bed and himself.

In all these cases, it is a sign of distress, which puts on its head the idea that carers have about their profession: here, medicine, which we practise with the aim of making our patients' lives better, is making their life hard.

This isn't only the case in dialysis... we could also talk about the transplant which makes life hard, chemotherapy which is exhausting, surgery which allows bodies which have fallen apart to survive...But (so as not to talk until lunch-time) I will limit myself to those situations where it is dialysis which really alters quality of life. Almost all the examples that I will give are taken from my personal clinical practice.

Let us try to describe those diverse circumstances – or the diverse mechanisms – which result in medicine making life hard:

A) Dialysis makes life hard because the only available therapeutic solution is a burden for the patient undergoing dialysis

Chronic dialysis was first done on the 9th March 1960 in Seattle.¹ The patient was 39 years old. He was dying when they started his first filtration session. But he had no other health problems other than his renal disease. Dialysis relieved his crisis. Then, since the machine was taking the place of his sick kidneys pretty well, he was able to continue to live a healthy life.

All patients on dialysis half a century ago were like him: they were young, with a healthy body other than the fatal destruction of their kidneys. The long dialysis sessions stole a lot of time from them, but between sessions, their quality of life was good.

One can't say the same thing about patients on dialysis nowadays, because they are, for the most part, elderly and afflicted with several illnesses or handicaps in addition to their renal failure. Under these conditions, dialysis allows the patient to survive, but cannot offer a good quality of life: a treatment which historically offered a miracle to young patients, is now used to prolong a life that is hard, and even one that is getting harder, in patients who are not in full health: in this sense, one could consider that our medicine, by delaying death, 'creates' or results in lives that are difficult.

What of the illnesses or handicaps which currently appear in addition to renal failure nowadays?

In certain dialysis centres, 68% patients are also diabetic, 37% have vascular disease, 36% are depressed and 22% have dementia.²

Doctors who specialise in handicap observe that in patients with physical handicap, the quality of life is, on average, better than people in full health,³ probably because physical handicap brings with it resilience. This is generally not the case in patients on dialysis. This is supported by the high number of patients with depression: 36%, a percentage which seems to me rather an under-estimate of the true figure.

What happens, for example, when a patient on dialysis also has diabetes?

Or vascular disease in their legs?

Or vascular disease in their arms?

There is a risk of becoming an amputee while already having renal failure. That combines to form a heavy burden! The best way of fighting the risk of amputation, would be physical activity. But it is very difficult for a patient on dialysis to exercise their muscles: every other day, they are immobilised in hospital. The other days, they are tired and can't exert themselves much. Vascular disease often gets worse, making amputation necessary.

Many of my patients on dialysis are double amputees.

¹ Before 1960, the technique of dialysis already existed, but it was only used in patients with acute renal failure, whose renal injury was only temporary, and would heal spontaneously within several days or weeks. Dialysis was only therefore needed for a brief time, after which the kidneys started functioning again. We could do temporary dialysis before 1960. But it wasn't possible to dialyse someone for several months or years (chronic dialysis). Patients with chronic renal failure therefore inevitably died.

- The first human dialysis was done in 1924 by Georg Haas (Germany), with no benefit (it lasted only 15 minutes).
- The first dialysis aiming to treat acute renal failure (16 patients) was done in 1943 in Kampen (Holland) by Wilhelm Kolff. All attempts failed.
- The first dialysis which succeeded in saving the life of a patient with acute renal failure was done in 1945 by the same Kolff.
- The first dialysis of a patient with chronic renal failure was done by Beldig Scribner (Seattle) in 1960, with one patient surviving 11 years.

² Kurella, Tamura et al. N Eng J Med 2009; 361:1539-47

³ C. Robert Cloninger, MD, Washington University in St Louis, Geneva Conference on Person-Centred Medicine, 29-30 May 2008.

Twenty or so years ago, articles on nephrology called amputation the '*new curse*' which came to strike our patients on dialysis and radically alter their quality of life. It was described as '*an epidemic of amputations*'. In a unit which is 'busy', such as mine, we must keep a whole area specially for the wheelchairs and prostheses of the 15 patients who come to each dialysis session.

Walking with a prosthesis is in theory possible with training. In reality, many dialysis patients will never walk following amputation. They lose their autonomy: the patient is confined to bed in the hospital and to their armchair at home. A major physical handicap is added to the constraints of the dialysis itself, which I haven't yet covered in any detail, and which are multiple:

A patient on dialysis will spend almost half their life undergoing medical care, for, in addition to the hours spent on dialysis, they spend hours in the taxi or the ambulance. They spend time preparing themselves and getting undressed before the dialysis session. Taking them off the machine at the end of the session also takes time, sometimes a lot of time. For example, when the fistula carries on bleeding at the end of dialysis...

Or the patient may need to rest before being in a fit state to get in their taxi because of hypovolaemia or fatigue, otherwise they risk having a funny turn or fainting.

There are also the dietary constraints: a patient on dialysis must constantly limit the amount they drink. They must eat no salt. They must reduce the amount of fruit and vegetables they eat, which are dangerous for them because of their high potassium content. Often, they also must reduce their calorie intake. The pleasures of dining are no longer available to them.

Besides this, most patients on dialysis have to come into hospital several times a year for multiple complications, or because of associated illnesses.

I am therefore not at all surprised to hear certain patients on dialysis say to me, repeatedly, that it is not worth living such a life: '*Unhook me Doctor, I want to go home!*' Or also: '*I want to die as soon as possible!*' I have also dialysed several people, who, in contrast, didn't say a single word; a most eloquent way of expressing the fact that they were in an unbearable situation. In both cases, one could say that these patients are depressed. Their generalists treat them with anti-depressants, sometimes without their knowledge. But is this mental suffering really a psychiatric illness? I don't think so. The despair, the desire to die and the insomnia in these patients seem to me to indicate that they have a normal affect and still possess capacity. A psychiatrist could probably help them. But shouldn't we first ask the psychiatrist what he thinks of a health system which recommends a treatment to patients with chronic disease which sometimes resembles torture? To such an extent that they need pain-killers, sleeping pills, anxiolytics and anti-depressants! One psychiatrist, Edouard Zarifian, points out those situations where mental suffering deserves respect: it belongs to the individual. Suppressing it systematically and brutally using medication seems to him to be a '*genocide of the human spirit*'.⁴

And what about the cases where there is real mental disorder or psychiatric illness? This is the case when dealing with patients on dialysis who have psychosomatic illness, patients with dementia, with personality disorder, with alcoholic brain damage. In these situations, the mental handicap or lack of education prevent the patient from understanding his treatment. He cannot cooperate with the nurse or the doctor. The medical staff are perceived thereafter, not as people there to help, but as persecutors. Rather than a saving act to be accepted, dialysis appears as a torture being imposed under duress. I had to dialyse a patient with mental handicap who was non-cooperative for about 10 years. I was obliged to do the will of administrators who were threatening me and on many occasions, I had to accept that we put restraints on his hands, his feet and his torso.

Other than when he is too violent, I am currently dialysing a man in his fifties who is an alcoholic with mental handicap. Sometimes he resists dialysis with violence. From time to time, he throws insults at me which would make you blush to hear (and which would have been a challenge to translate for my remarkable translators). Other times he promises that he's going to make sure I need the services of a good maxillo-

⁴ **Edouard Zarifian**, *Paradise in our head (Des paradis pleins la tête)* Paris, Odile Jacob (Pachès), 1994

facial surgeon. All this disinhibited violence is evidence of his misery at having to undergo dialysis, since his debility and the alcohol render it impossible for him to get used to a treatment which is so constraining. Nonetheless, even if dialysis is intolerable for him on certain days, he isn't indifferent to the pleasures of life. He's managed to marry a lady from Madagascar who was looking for a marriage of convenience to obtain a French residence permit (a racket which, in fact, is not uncommon amongst patients of both sexes on dialysis in France). The situation has a certain vaudeville aspect since this defiant, impulsive (and unhappy) patient comes asking me to give him medication to improve his erections, whereas his wife who entered this marriage of convenience begs me not to prescribe him anything....

For a nephrologist, the mediocre or frankly bad quality of life of patients on dialysis is evident to him every day. But other doctors are not aware of this. They don't hesitate to prescribe drugs that they deem useful, but which are nephrotoxic and which will precipitate the patient towards that quite unique and demanding life of a patient on dialysis. For example, anti-coagulants. They are prescribed for a cardiomyopathy, but sometimes they threaten to destroy the kidneys within a few weeks by causing cholesterol emboli to the kidneys...and at the same time to the big toes.

Even given this alarming scenario, the nephrologist will not succeed in stopping the prescribing of these anti-coagulants, for they are, in general, very useful, but very dangerous in individual cases. Many doctors don't realise that dialysis is an extremely demanding treatment.

Some patients on dialysis have a long time without trouble. But complications will generally ensue sooner or later. And they take all sorts of different forms:

- Some patients on dialysis have a fistula, created by a surgeon. This allows the blood to circulate through the dialysis machine with the high flow rates which are required.
- Frequently this fistula deteriorates. Sometimes it dilates. Often it shrinks, which then necessitates further interventions, sometimes more than once, more or less taxing for the patient.
- On other occasions, the fistula blocks, or results in a thoracic vein occlusion.
- Fistulae can haemorrhage. This can be major and distressing for the patient.

The patients are often distressed in these situations, which happen often, where their fistula is not functioning properly, even if we take care to tell them that we can always find a solution. They think that our solutions are a bit too distressing and don't last long enough. They are not wrong.

In some patients, we replace the fistula by subcutaneous catheters.

With indwelling lines, their quality of life is definitely worse, since complications are more frequent and more life-threatening:

- Some catheters get infected
- Sometimes the catheter gets infected because the patient with dementia has pulled the line out without realising what they were doing.
- Commonly the catheter doesn't work well, for example, because it is kinked;

When a catheter isn't working well it can make dialysis hellish for weeks or months. Each time he comes for his dialysis session, the patient asks himself anxiously if the dialysis session will go alright, if it will allow him to go home. Or if the line will have to be repositioned or sewn back in. Or if he will need a new line. Or if he will need to have an operation or come into hospital. He is tossed around, at the whim of complications which are never-ending.

To be sure, these downsides of dialysis don't affect all patients on dialysis, or all the years of life gained thanks to dialysis: this is what a wise ex-employee of the post office, who was dialysed between the ages of 83 and 89 told me. He could barely walk. But he knew how to appreciate the quiet of his dialysis sessions, and said: *'Dialysis gives me beaches full of freedom to think and to read: I have four hours all to myself. In my life, I have never had that, had four hours to myself; there was always something else for me to do.'*

And again, a young teacher, forty or so years old, who very nearly died because of a renal transplant that went wrong: *'Dialysis three days a week, it's great: on the days where I come for dialysis, the nurses are so kind that it feels like I'm with family. I really appreciate that. And the days where I'm not having dialysis, I really make the most of them: I'm happy, I work, I live at 200%.'*

But the topic for today, 'When medical care prejudices quality of life', concerns patients on dialysis who don't have that good fortune: those who have entered an upsetting process of slow, inexorable physical decline. As the months and years go by, the doctor makes their life harder and harder: I was full of admiration for the courage of a young woman who required dialysis as a consequence of cancer of the uterus. Radiotherapy cured her cancer, but damaged her ureters and her bladder (and thereby her kidneys) as well as most of her intestine. She was no longer continent of urine or faeces. She had to give up the activity which gave her greatest joy, swimming. To eat had become almost impossible for her. She was therefore malnourished, weak, and hardly left her bed between each dialysis session. She was almost a skeleton. But her dignity, her gentleness, her philosophy impressed all those around her. She decided herself the moment at which her life became too hard to be worth living. She decided to stop dialysing and to die. That fine mastery of their destiny is rare amongst our dialysis patients. This is in part because we, the doctors, don't know how to help our patients in their crucial choices. Seemingly, we have become incapable of thinking of what is essential in life, because we are always battling against death. Except, perhaps, when we are ourselves threatened by an illness which leads to decline and death. For when we are in this situation, we must define what gives life enough purpose to continue living, just like my young dialysis patient following radiotherapy. *'What makes life meaningful enough to go on living?'* This is the question posed by a neurosurgeon, Paul Kalanithi, in an extraordinary book which Kathy introduced me to, *'When breath becomes air'*.⁵ *'How much suffering should we allow a patient to endure before saying that death is preferable?'*, asks this neurosurgeon, himself suffering from an incurable brain tumour.

How can we help our patients when treatment makes life hard for them? The main way, is to listen to them and to talk to them.

- Listening to them isn't always enough to understand them better, since their conversation is often lacking in clarity and consistency. But it transforms our role as doctor-repairer into doctor-who-accompanies.
- As for talking to them, this isn't about lavish encouragement for a patient who is expressing their discouragement, as practised by many care-givers. This would be the same as doubting their sincerity, minimising the importance of what they are saying. I prefer to give a reply which you may find sadly resigned, but seems to me to be more respectful of the depths of despair expressed by my patients; *'Yes, it's true, you have a lot on your plate at the moment.'*

Nonetheless, when a patient asks me to unhook them, assuring me that they want to die, I must confess that, I, too, minimise a little his complaint:

- For I point out to him that he was exercising his free will when, today, he got in the taxi to come to the dialysis centre.
- I also lavish a sort of encouragement on a patient wanting to have his despair heard, since I reply that if he really wants to be taken off dialysis to die, it will cause us pain. Those of us who care for him and have been dialysing him for a long time know him and hold him in esteem.
- If the patient is from my culture, I talk about a fable from La Fontaine, *'Death and the woodcutter.'* This fable is well-known by all French people who will have learned it in childhood at school. It describes an old woodcutter bowed down by his miserable life. *'unable to put up any longer with striving and pain (...), he thinks on his misfortune (...), he calls for Death.'* But when helpful Death arrives, the woodcutter changes his mind. He sees, that taking everything into account, he prefers to stay *'in hac lacrymarum valle'* than to pass straight on into a better world. He saves face by

⁵ Paul Kalanithi, *When breath becomes air*. The Bodley head ed. (London), 2016, p71

pretending that he has just called Death to help him to load onto his back a heavy load of wood, rather embarrassed to have disturbed him for nothing... For *'It is better to suffer than to die: that is mankind's mantra.'* This short fable is an essence of philosophy, which generally helps my patients to understand that when they ask to be taken off dialysis, they are expressing a deep despondency which is not really a true desire to go as quickly as possible to the cemetery.

- The nurses have little gestures which sooth even those who are making dramatic complaints. Currently, they have resorted to a strange practice: massage with oils. It's irrational, but not to be sneezed at.

But what to do in those few cases where the desire to end their life seems settled (given that it doesn't change with time), and when it seems reasonable (because the continued life of that patient on dialysis seems awful)? In such cases, I don't say good-bye, so as not to back the patient into a corner. I explain to those around him what he is going to suffer, the end being in principle rapid and without discomfort if one pays attention to certain precautions, such as not eating salt. The family, or the staff at the retirement home, need to be given these technical pointers. As remarked by Montaigne, we need the doctor's knowledge so that death is not too hard a moment, just as we do at the time of birth.

B) Dialysis makes life hard when the medical treatment plan is promethean

For medicine to make progress, we need new ideas and intrepid doctors. Several nephrologists tried to do renal transplants in the 50's⁶, in an era where transplant doctors didn't know much about immunology, and didn't understand organ rejection. In consequence, transplants always failed, the transplanted patient died except if they had received the kidney of a twin brother. On the other hand, patients with renal failure who were not grafted always died as well since chronic dialysis didn't yet exist. This is why the Frenchman Jean Hamburger, nephrologist and philosopher defended these high-risk grafts, and justified himself by saying *'it is in this way that medical science makes progress (...) In cases of fatal illness, the doctor has (...) the right to try everything. In this case, morality consists in being as daring as possible.'*⁷

Maybe. But when the doctor is bold, it's the patient who takes the risk and eventually suffers. It is the patient whose life is made hard by the reckless doctor, not the doctor himself. Here are two examples of reckless dialysis:

⁶ History of renal transplant:

- 1933 : first human renal transplant- Voronoy (USSR) transplants a kidney into a 26 year old patient with acute renal failure secondary to consumption of mercury in a suicide attempt. Fails.
- 1947: first human renal transplant which is temporarily successful: David Hume and Hufnagel (Boston) transplant a kidney into a woman with acute renal failure secondary to a septic abortion. The graft only functions for two days, but that is enough for the patient to emerge from her uraemic coma. Another two days later, her own kidneys recover function.
- 1951: first transplant in France. 5 attempts (René Küss), 5 failures
- 1952: first graft with 'prolonged' success: Jean Hamburger (Paris) grafts a 16-year-old with his mother's kidney. The graft functions for 21 days. Then it is rejected and the young man dies.
- 1954: first graft with a truly lasting success: Joseph Murray (Boston) grafts a patient with chronic renal failure with the kidney of his identical twin brother. Excellent result.
- 1959: first successful graft with a non-identical twin donor. Merrill (Boston) performs such a transplant (between non-identical twins) thanks to total body irradiation of the recipient. A few weeks later, Hamburger uses the same method and has the same success (the graft functions for 27 years) with 37-year-old twins. Shortly afterwards, Küss and Legrain (Paris) are equally successful, but this time the recipient is a brother and the donor his sister.
- 1960: first successful graft with unrelated donor: René Küss (Foch de Suresnes hospital) succeeds thanks to immunosuppression.

⁷ **Jean Hamburger**, 13th November 1990, interview with Jean-François Picard, 'HistRecMed', www.vjf.cnrs.fr/histrecmed

- 1) **Dialysing a new-born** is technically possible. The technology is available. It is useful when a new-born develops acute renal failure, that is to say reversible after a few days or weeks. In this case we dialyse them for a short while. Then their kidneys get better, and they will never need dialysis again.

But one of my nephrologist friends found himself dialysing a new-born whose renal failure turned out to be chronic, that is to say permanent. In such a case, dialysis has to be permanent as well, at least until a transplant kidney becomes available. Until then, the treatment imposes a huge burden on the child and on their parents. Rather than embarking on such a course of treatment, it seems to me preferable to let the baby die at birth. We don't have the right to inflict on this small being a life so unnatural, repeated psychological and physical suffering, a terrifying way of life which he can evidently not understand.

- 2) The legitimacy of dialysis is also under discussion at the other end of life: is dialysis too tough a treatment to suggest to **very old people**?

To throw light on this question, a French study from 2003 established first of all that dialysis is effective in patient with renal failure more than 80 years old who need treatment with dialysis. If we start dialysis in patients in their 80's, they survive a mean of two and a half years with a maximum of eight years. If we don't dialyse them, their mean survival is only 8 months with a maximum of 3 years.⁸

Given these results, are we starting dialysis effectively in older people?

- In the U.S. this depends on their age:
 - Between 75 and 80 years old, dialysis is refused with no hesitation in 20% cases.
 - Between 80 and 85, in 30% cases.
 - After the age of 85, in half the cases. This is surely to avoid imposing a treatment which is going to make their life too hard on the very old.
- The same is true in Australia, in New Zealand and in Canada: the older the dialysis candidate, the more often they choose to let him die rather than treating him.
- And in Europe? France and Great Britain are two countries fairly similar in population and per capita wealth. It is likely that end-stage renal failure has a similar incidence in the island tea-drinkers and in the continental wine-drinkers. Yet, in France, we do a few more transplants and dialyse a great deal more. Is this because the Brits have more sense when it comes to treatments which make life hard? Is it because the French are happy to spend more on their health? In France, one patient dialysing at a renal unit costs 9,307 Euros per month.⁹

C) Dialysis makes life hard when the doctor institutes active treatment whereas withholding treatment would be more appropriate

Mythology teaches us that Aesculapius was a practising doctor, but he had a failing: he preferred action to inactivity. Many doctors nowadays have the same failing...

Aesculapius felt himself more at one with mankind than with the gods, even though he was the son of Apollo. Tending patients was his passion. This disturbed the order of the world, since the gods had already decided, contrary to this, to create a suffering (and violent) mankind in order to have before their eyes the entertaining spectacle of the world's misery. Don't let's be critical of them: we invented television for the same reason.

As long as Aesculapius was happy to cure simple illnesses, the gods tolerated this minor infringement of the natural order. But one fine day, Aesculapius decided to tackle a more difficult medical problem. Not renal

⁸ Joly D et al., J Am Soc Nephrol 2003; 14: 1012-1021

⁹ Study from 2003 on the cost of dialysis in France, published in 2005 by the National health insurance fund:

- Haemodialysis in a public facility : 111,689 Euros per year
- Haemodialysis in a private facility: 61,959 Euros per year
- Haemodialysis at home: 42,000 Euros per year

failure, for he probably foresaw that dialysis would need a sort of genius beyond him, possessed solely by nephrologists. More modestly, Aesculapius contented himself with wanting to be an intensivist, to bring the dead back to life. This meant abandoning an approach which is often the wisest thing to do in medicine, namely inactivity, in order to choose an approach which is often unreasonable, namely active treatment. Jupiter became annoyed that Aesculapius was throwing over the natural law of life and of death. He struck Aesculapius with lightning. We resemble Aesculapius. His over-activity is the original sin in medicine. He makes life hard for the patients.

Here are two contemporary examples of active treatment which involve nephrology;

- 1) First example: in the 1980's a new class of anti-hypertensives appeared, ACE-inhibitors. Today, they are prescribed for numerous patients with hypertension, heart failure, diabetes and renal failure because of their powerful cardiovascular protective effect. But they have a serious side-effect: if the patient taking an ACE-inhibitor becomes dehydrated they risk developing renal failure. For all that, few doctors have the good sense to avoid ACE-inhibitors in patients who are at high risk of dehydration, for example because they don't drink very much, are elderly, or are taking diuretics. The result is that, just like all nephrologists, for many years, I have had to treat as an emergency several patients a month whose renal failure is a result of taking an ACE-inhibitor. Sometimes they die. Sometimes, we have to dialyse them. Sometimes they just need a few days in hospital. In each case, a prescription has made their life hard. The reason for these treatments which are in theory beneficial, but in reality, toxic, is always the same: the person prescribing didn't know how to do nothing. Medication is a temptation which is difficult to resist.

Luc Perino, who gave one of the talks last year at Pilgrim Hall, and whose scientific erudition is impressive, worries about the inability of doctors to refrain from treating, observing that *'Each day shows us that advances in knowledge authorise inaction much more often than they do to active treatment.'*¹⁰

- 2) Second example of active treatment: **needless hospitalisation at the end of life**
When death approaches, ill-considered medical activism has particularly dire consequences for our patients: the dying generally suffer less and end their lives more humanely if they can spend their last days at home. This is particularly true for patients on dialysis, for in this situation, the evolution of the disease is completely predictable, and the care required is simple and well-established. Despite this, patients on dialysis are often taken from their homes or their retirement homes to hospital at the time of death. This results in a needlessly hard end of life, unless they are looked after by palliative care services.

One study amongst many even shows that the death of patients on dialysis is more uncomfortable than that of other patients at the moment of death:

- In their last week of life, 76% patients on dialysis are hospitalised, compared to 61% patients dying from cancer.
- 49% dialysis patients spend time on intensive care compared to 24% patients dying of cancer.
- 45% dialysis patients die in hospital versus 29% patients dying of cancer.

We might find it surprising that Jupiter doesn't sometimes strike down with lightning those doctors who have wrenched a dying dialysis patient from their home in order to subject them to active treatment on an intensive care unit.

D) Dialysis makes life hard when it neglects the patient's autonomy and liberty

I have already talked about the unbearable situation where, under pressure from administrators, we are forced to dialyse an adolescent psychiatric patient who has refused treatment. We put him on dialysis while

¹⁰ Luc Perino, Medical moods, Félin editions © 2007, Club France-Loisirs 2006 (page 14 in the edition of France-Loisirs)

in restraints. It is a real battle. He shouts his opposition to this during the three hours of his dialysis session. We are forcing dialysis on him. The hospital Director is happy. He feared legal proceedings in a case of death due to refusal of treatment by this patient lacking capacity. That danger has been averted. Too bad if the patient must suffer for three hours. Too bad if the scenario has been playing over and over for several years.

I also dialysed an elderly patient with vascular dementia for several years. He was bed-ridden and aphasic. He was hardly able to communicate with anyone. Obviously, he tolerated badly a treatment which he couldn't begin to understand.

I also dialysed a depressed patient for a long time, against his wishes, whose desire to commit suicide was unshakable. Each time an opportunity presented itself, he attempted suicide. He threw himself out of a first-floor window after a dialysis session. A few months later, he escaped from the psychiatric nurses watching over him, to throw himself under the cars in the nearest road. We almost had to laugh in the midst of this tragedy, since he escaped without a scratch, whereas people were injured in the ensuing chaos which he had caused.

Why do we practise such insane medicine? Because it isn't insane in the eyes of all the world. I consider dialysis to be a taxing, complex, lengthy treatment, which by its nature means that the patient on dialysis must be capable of finding out about it, giving their consent and cooperating with the treatment. If these conditions are not met, I think that non-dialysis (in other words death) is preferable to the thrice-weekly imposition of treatment by force, with its burden of suffering and humiliation forced on the patient. But not all nephrologists hold this opinion. Who is right? There is no simple reply, and debate ventures on sacred ground. So, it won't be tomorrow that dialysis by force stops making life hard, or even intolerable for certain patients.

All the same, it does happen that we decide to stop dialysis, to let the patient on dialysis die, because their quality of life is so impaired. And also, because we can sense that the patient no longer wants to be treated, whether they say it or not.

In France, the deliberate interruption of dialysis represents 17% of causes of death amongst patients on dialysis. On average patients die 10 days after the decision to stop dialysis. Of course, this decision is taken in discussion with the patient. But there remains uncertainty, or at least some things that are left unsaid in this discussion, since in only 15-22% cases is the decision clearly taken by the patient refusing to continue treatment: *'Unhook me, doctor, I want to go home!'*

E) Dialysis makes life hard when society's rules force it on someone

It seems to me that nowadays society tries to impose three unrealistic conditions on doctors: to deliver perfect care, to do it fast, and to do it cheaply.

There is enough here to send doctors mad (and maybe the process is already well underway!). There is also enough here to make life hard for our patients.

1) The injunction to deliver perfect care

All humanist or religious philosophies exhort us to be the best possible. Aloys von Orelli reminded us at the meeting of *Medicine de la Personne* at Saint-Prix, of the universality of this injunction: *'All religion has at its origin the sentiment, carved into each person, that they are called to do Good. This sentiment is called 'the great Memory' since mankind remembers it ever since his 'fall'.*¹¹

Nowadays, to ensure that doctors give perfect care, society multiplies the rules, the safeguards and the regulations. Sometimes this represents progress, but it also has negative consequences which help to make life harder for the patients:

¹¹ Aloys von Orelli, meeting of *Medicine de la Personne*, Saint-Prix (Val D'Oise), 23rd July 1997

- a) **First example** : the degree of comfort of a patient on dialysis depends mainly on the quality of their fistula.

A good fistula permitting the patient an excellent quality of life for many years has become rare...because of the desire to do things well.

Nowadays, renal patients frequently come into hospital years before they need dialysis. During each of these hospital stays, they nearly always have a venous catheter ('venflon'). Such is today's medicine: no longer do we take blood on multiple occasions with a simple needle (this is old-hat, considered archaic).

We prefer in-dwelling catheters (it's modern, so necessarily better). We know that venous catheters that stay in several days generally damage or destroy the veins. The result is that several years later, the day that our patients need to go on dialysis, all their veins are damaged. It's no longer possible to make a fine fistula for them. Their fistula is mediocre, narrowed in some parts, dilated in others.

Because of these poor-quality fistulae some patients embark on a real nightmare. They haemorrhage, must undergo multiple surgical interventions, are often hospitalised, suffer from endless infections which are sometimes fatal.

- b) **A second example** of the perfectionist viewpoint which makes life hard has to do with transplantation.

This is a difficult moral problem: France takes in numerous sick foreigners who cannot be treated in their country of origin because of poverty, war or inequality. In particular, France takes in patients with renal failure who need dialysis or renal transplantation. Most of them come from Eastern Europe or Africa. Most of them are young. So, for them transplantation is preferable to dialysis. They are therefore transplanted more willingly than the French patients with renal failure, who are inferior transplant candidates because they are older and frailer. Now, the lack of donor kidneys is an insoluble problem for French patients with renal failure, which is getting worse every year. There are more than 16,000 people on the transplant waiting list, whereas there are only 3,500 donor kidneys available per year.¹² Taking in sick foreigners is in sort a moral imperative... which however has immoral consequences: it makes life hard, even very hard, for thousands of patients on dialysis for whom being on dialysis represents torture, and transplant their sole hope of a good life. Under current circumstances this represents a hope very far from reality.

Faced with this growing problem, I think back to a remark made by Rutger Meijer the year that *Medicine de la Personne* met in Schoorl, concerning care for sick foreigners: *'there is an exaggerated charity which creates chaos: all the people on earth can't go and live where the soup is better simply because 'they have the right to do so'*.¹³

- c) **Third example** : the growing use of protocols:

The desire to do better, most notably encapsulated in the French legal principle, the 'precautionary principle'. Has led to a proliferation of medical protocols. Usually, following a protocol should act as a guarantee of good quality. However, that codification of systems of care can also make our patients' lives harder. How is that so? This is a subject dealt with in the session at Woltersdorf in 2015:

- Protocols describe, by definition, the best way to treat the majority of patients. But not all of them. And yet care-givers have a tendency to believe that they need to apply them to 100% patients.
- One can see that 'protocolisation' often exempts doctors from having to think, increasing the risk of error.

¹² Number of patients on the transplant waiting list in France, and number of patients receiving grafts:

- In 1990: 4,677 waiting, 1,949 grafted
- In 2000: 5,000 waiting, 1,924 grafted
- In 2010: 7,616 waiting, 2,892 grafted
- In 2015: 16, 529 waiting, 3,470 grafted

¹³ **Rutger Meijer**, Schoorl, Netherlands, 29th August 2013

- 'protocolisation' infantilises caregivers and can weaken the essential driver of their vocation: the desire to put oneself at the service of those who are suffering.
- Sometimes, protocols give the doctor an excuse to take a decision which he knows is not in the patient's best interest.

This invading protocolisation can make life hard for our patients. For example, our patients undergoing dialysis are probably in less good condition than previously (more malnourished, with worse hypertension, more tired...) because quality protocols which were ill thought out and above all poorly understood, have led to a dangerous reduction in the duration of their dialysis sessions.

d) Another example: in order to be regularly nursed at home, a patient may feel obliged to get a 'hospital bed'. This is almost becoming the rule, since it makes the nurse's work easier. But is traumatic for the patient: not only does he have to have a bedroom which resembles a hospital room, but he is also obliged to give up his own bed, with its many memories, which he has slept in for decades.

2) We need to treat quickly

In 2017, in France, a consultation with a generalist lasts 17 minutes. This isn't much, given that in France a large part of the consultation is devoted to administration.

In Great Britain, the length of the consultation is possibly shorter still, but the doctor has assistance with certain tasks...and patients are asked to come back if there is more than one medical problem.

Does this requirement for speed make life difficult for the patient?

In order to reply, just imagine ourselves as the patient going to see the doctor....

It seems to me to be difficult to practise medicine of the person while hurrying. A Vietnamese proverb says that *'it is easier to make one child in 9 months with one woman than, in one month with 9 women.'*

3) We have to offer treatment without it being expensive

In our countries, the cost of medical care is high.

- 6,935 \$ per person per year in Switzerland
- 5,694 \$ in Holland
- 5,267 \$ in Germany
- 4,407 \$ in France
- 4,003 \$ in the UK
- 2146 \$ in the Czech Republic.¹⁴

The increase in these costs worries policy makers. Everywhere, people are trying to slow down the increase in costs, and in general, it makes life hard for certain patients.

Medicine stops being human in order to become principally mercenary and industry-driven. This is a quasi-official objective: in France, a urologist acting as adviser to the Ministry of Health wrote: *'I am convinced of the necessity for medicine to transition from being a medical craft to a healthcare industry in order to improve the service we offer.'*¹⁵

Most doctors in positions of responsibility can see that this politics of profit-loss causes considerable harm to the patient.

- It *'transforms hospitals into inhumane machines'*, notes the president of the doctors in the university hospital at Montpellier.¹⁶

¹⁴ Calculations from the OECD of costs per person in 2016, including non-reimbursed expenses (except for the Czech Republic: calculation from WHO in 2014)

¹⁵ Prof. Guy Vallancien, 'Health is not a right.' 2007

¹⁶ Bernard Guillot and Pierre-François Perrigault, president and vice-president of the departmental evaluation committee at Montpellier university hospital, April 2010.

- *'The result sends a shiver down my spine. We are moving towards a system which is defective, ineffective, and in the end dangerous,' says the president of the doctors from all the hospitals in Paris.*¹⁷
- With payment by results, *'it is more profitable to dialyse a patient than to prevent them from needing dialysis,'* concludes a professor of endocrinology, who has lost his funding to help prevent his patients progressing to needing dialysis.¹⁸ He also warns that we risk passing from the époque of the administrator to that of the CEO (managing director).¹⁹
- *'We have moved from the culture of a patient who costs to the culture of a patient who brings in money,'* laments the President of the National Committee of Ethics.²⁰

To summarise, nowadays, the changes in the way we finance care, and therefore in the organisation of healthcare, threaten to make the life of the patient harder and harder.

F) The personality of the doctor²¹ can make the patient's life hard

Let's not pull wool over our eyes: in addition to the hardship of the disease, in addition to medical error, in addition to inappropriate social rules, it is possible that the doctor himself can make our patient's lives hard.

There are doctors who are indifferent to their patients' psychological needs.

There are doctors who ignore physical suffering. There are even doctors perverse enough to rejoice in it. I have seen this medical sadism practiced by a cruel professor of medicine. His orders, which were impossible to discuss with him, ended up needlessly torturing the patients, in front of their families, without anyone being able to stop him. In 2008, at Fredeshiem, Claire Mestre assured us that doctors had to be aware that they could derive pleasure from suffering.

There are doctors – and one can understand why – who's greatest concern is their pay, their career, and their private life, and who will put all of these ahead of the care given to the patient.

Maybe doctors with a pessimistic mind-set have an involuntary nocebo effect: Richard Henderson-Smith pointed out at Weggis that *'if the doctor does not think himself that his patient has the capacity to 'pull through', then the patient will effectively not pull through'*.

And the placebo effect? Perhaps doctors who are too rational are incapable of helping their 'psychosomatic' patients, whereas, as noted by Friedhelm Lamprecht: *'it is a fact: 80% of patients' symptoms cannot be medically explained: spiritual factors are important'*.

Maybe doctors with an impatient nature, wanting above all to be efficient, make life a little bit hard for their patients. For as said by Pierre Carnoy, in the era where he was primarily a geriatrician, before being car mechanic and body-work specialist: *'If patience is not present, there is violence'*.

¹⁷ **Prof. Pierre Coriat**, president of the departmental evaluation committee of the Paris hospitals, 17th March 2009, concerning the proposals of the Bachelot law (HSPT) which abolishes the power equilibrium between doctors and administrators in hospitals.

¹⁸ **Prof. André Grimaldi**, diabetologist (Pitié-Salpêtrière), *Quotidien du Médecin*, 30th April 2008: he is talking about patient education about their diabetes, which payment by results discourages.

¹⁹ 'The power of the medical director is legitimate, ours is also. We will not progress from the era of the administrator to that of the CEO, this is what we need to fight against.' Prof. André Grimaldi, diabetologist (Pitié-Salpêtrière), March 2006, General Assembly of Parisian hospital doctors opposed to the Bachelot law which gives all powers to the hospital director.

²⁰ **Didier Sicard**, professor of internal medicine, *France Culture*, 22nd December 2012

²¹ And also the personality of a spouse: the wife of a patient who became tetraplegic after a car accident rejoiced loudly in her husband's frightful handicap (he had a mistress): 'Like that, you won't be able to cheat on me anymore!'

G) Conclusion to temper all that has gone before....

Disease makes life hard, we know it well...

Medicine can end up also making life hard: that is the theme of our annual meeting, and I have just given you plenty of illustrations.

This is not something to rejoice in. It risks making us forget a truth: when life is made hard by illness, or medical care, or both, there are certain patients who grow in stature as a result of this experience. William Faulkner expresses this resilience when he says, *'With the grain of sand which wounds, the oyster manufactures a pearl.'*

If this positive aspect didn't exist in our patients, I would personally be overcome by the harshness of the lives of a good number of my dialysis patients.

That is why, to finish with, I am going to tell you the amazing journey of one of my patients; it makes one think of William Faulkner's oyster.

He is a 48-year-old man: he is in perfect health. He looks after a modest shop with his wife selling magazines and books. He is a small-time, over-worked business manager, perpetually anxious and stressed: he scolds his spouse wanting her to be more efficient, he smokes a lot.

Because of this, his arteries are not in a good state, but he doesn't know that, neither do his doctors, since he has never had any symptoms. Someone decides it would be a good idea to do a coronary angiogram on him.

He arrives in the hospital the day before, in good health. The following day (day 1), he has his coronary angiogram and the catastrophe happens: the investigation dislodges an atheromatous plaque giving him a huge heart attack. The following day, day 2, he has surgical coronary bypass. But his severe cardiac failure means that he needs circulatory assistance. For this, he has an aortic balloon pump inserted via his femoral artery. The balloon pump results in a series of arterial emboli. He ends up with renal necrosis, mesenteric infarct and leg ischaemia. On day 3, he has an emergency cardiac transplant and starts dialysis, which will be permanent.

On day 9, he has a large part of his necrosed intestine resected: a part of the ileum, all his colon, and part of his rectum. The surgeons are obliged to create an artificial anus, which will also be permanent.

His two ischaemic legs will in the end necessitate above knee amputation.

During all the years that I dialyse him, his troubles multiply. He is operated on four times to create a fistula: the surgeon fails four times. All the liver and heart biopsies, done because of his heart transplant, are technical failures. He has to close his newsagents shop, and no longer has any income. With his bilateral amputation, he can't drive. Without intestine, he is malnourished and lacks strength. In addition, he lacks courage – with good reason – and he has a difficult character. This isn't all: one day when he is having dialysis, lightning strikes his house and damages it.

Here therefore is a young man, physically hyperactive, who was not ill, who from one day to the next, found himself on dialysis, without intestine, without legs, without money, without a job and with someone else's heart. It makes you think of Job. But all Job had was a skin condition, probably psychosomatic, not serious, and which got better on its own without the intervention of a dermatologist.

Try to put yourself in the place of this man. How would you cope with such a radical reduction in what you were able to do?

Well, several years later, even though his physical state was no better, this is what this patient on dialysis confided in me: *'I have been fortunate to have all this happen to me. It has changed me. If none of it had*

happened to me, I would have stayed an idiot...'. He is referring to his go get attitude, which had forged a purely utilitarian concept of existence in him.

Anyone would have thought that a disastrous coronary angiogram had made his life hard...

Anyone, except him!